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DISSERTATION

THE KNOWLEDGE, ATTITUDES, BELIEFS AND PRACTICES TOWARDS
PALLIATIVE CARE OF FAMILY PHYSICIANS IN THE BOLAND AND
NORTHERN SUBURBS OF CAPE TOWN.

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ABSTRACT

Introduction: Palliative care, for those dying from a life-threatening disease, has developed to become a definite discipline in mostly developed countries. Through this palliative care has become accepted as a human right to all in need of end-of-life care. The stark reality in developing countries is that palliative care is in the early stages of development, with the result that if it is available at all, it usually is very basic. These countries which have restricted resources available are faced with an increased and overwhelming demand for palliative care because of the AIDS pandemic and also an expected massive increase in the incidence of cancer and non-communicable diseases. This raises the question how this demand will be met? The WHO is again looking at primary care as the way of meeting increased health care demands, including palliative care. The importance of the role of the general practitioner in delivering palliative care is widely accepted. The greatest majority of general practitioners in South Africa have never received official palliative care training. The question to be answered then is how well are they equipped to meet this increasing demand for end-of-life care.

Methods: The study was designed as a descriptive cross-sectional KAP study. The study population was defined as all practising GPs working in a particular area in the northern suburbs of Cape Town and a number of Boland towns. The data collection tool used was a self-administered questionnaire that was developed through a process of review and through a pilot process. The questionnaire was then posted to all identified GPs with a return envelope with follow-up of non-respondents to ensure a better response rate.

Findings: The response rate was 34,7%. Overall 69,45% of the questions were answered correctly and 30,55% incorrectly. The respondents showed good knowledge on morphine use and respiratory depression, the dangers of addiction to morphine, emergencies in palliative care and spinal cord compression. The greatest majority of respondents do not

understand the holistic approach to pain management and also do not have knowledge about the use of syringe drivers. A high percentage of participants have a positive attitude towards palliative care in general, feel comfortable with their own emotions in end-of-life care and acknowledge their need for further training. On the questions on belief, respondents believe that the family must be involved in decision-making and that the GP must be doing bereavement care. Unfortunately most participants believe the management of physical symptoms ensures quality of life and seem not to grasp the holistic approach followed in palliative care. In practice only a few respondents understand the routine use of anti-emetics with initial opioid prescriptions. There is a significant number of GPs uncertain about the use of combinations of analgesics, the use of intravenous fluids in end-of-life care and the use of the subcutaneous route to administer drugs and fluids.

Conclusion: Participants have an overall positive attitude towards palliative care, but they lack knowledge in certain areas. They also have some wrong practices and beliefs that will affect the quality of the palliative care delivered.

Recommendations: The importance of the role of the GP in palliative care has to be recognized and acknowledged by all involved in such care. Programmes have to be initiated to train and educate practising GPs in palliative care to empower them and also to spread the end-of-life care message.

INTRODUCTION:

The World Health Organisation (WHO) has formulated the following definition of palliative care: Palliative care is an approach that improves the quality of life of patients and their families facing problems associated with life-threatening illness through the prevention and relief of suffering, the early identification and impeccable assessment and treatment of pain and other problems physical, psychosocial and spiritual¹.

The development of palliative care:

Palliative care as we know it today has close links with the hospice movement, which originated in the late fourth century as places where pilgrims were cared for, but where the sick and dying were also welcome². Over many years this developed into the modern day hospice movement where the primary aim is the care of the dying and their families with the focus on the quality of life until death as explained in the definition on palliative care above. The main objective is “quality of life until death” and the message is: “you matter because you are you, and you matter until the last moment of your life. We will do all we can, not only to help you die peacefully, but also to live until you die”. It was recognised as a field calling for specific interventions and skills. With this, a wide holistic approach to patient care was accepted, as underlined by the concept of “total pain”, meaning that pain and patient care has physical, psychological, social and spiritual elements and that those patients with life-threatening disease, have needs in all four of those areas. This then forms the basis of palliative care.

Attitudes towards death have changed through time from the Middle Ages to the present. From something to be accepted as the natural course of life, to something to be feared, with an increasing tendency not to tell the dying person the truth about his/her condition. The result is that people end up dying in hospital, alone, rather than at home². Death became a forbidden subject and a sense of outrage grew that modern advances are unable to stop the inevitable, which is to prevent death. As Kubler-Ross writes: “ we would think that our great emancipation, our knowledge of science and of man, had given us better ways and means to prepare ourselves and our families for this inevitable happening. Instead the days are gone

when a man was allowed to die in peace and dignity in his own home. The more we are achieving advances in science, the more we seem to fear and deny the reality of death “³. This may easily apply to developed countries where, because of ageing populations, there will be an increased need for palliative care in the future; caring for those facing death to come to terms with the end of life. In England and Wales, for instance, where home-deaths are decreasing, this need will have to be met by increasing medical facilities or by a growing and expanded home-based palliative care service to help and care for people facing the inevitability of death⁴. In these developed countries, patients will still have the choice of expressing a wish for the place to die, whether it is in a palliative care unit, hospital or at home ². In Africa the luxury of this choice is not available to people suffering from life-threatening disease. Hospitals are overcrowded with patients because of the HIV/AIDS pandemic, making it unrealistic to expect formal health care facilities to provide palliative care at community or home level⁵. The extent of human suffering because of HIV/AIDS and cancer is tragic and the WHO sees the provision of palliative care “as an urgent unavoidable humanitarian responsibility”, which also reflect the values of society locally and globally. Countries in the developing world provide limited or no palliative care, experiencing obstacles like insufficient availability of opioid drugs because of ignorance, false beliefs and pricing and regulatory obstacles. In these resource-poor countries with poor healthcare infrastructure, home-based care may be the only means of providing adequate access to palliative care, if at all.” One also has to realise that within certain cultural groups it may well be the choice to die at home⁶, with or without palliative care.

Palliative care as a human right:

This lack of provision of palliative care stands in stark contrast to the argument by Margaret Somerville that the relief of suffering is a common goal of both human rights and medicine and that therefore the relief of pain and suffering of people with a life-threatening disease is also a human right⁷. Some proponents of this argument feel that the protection of human rights and health are closely entwined, while critics argue that in a resource scarce world this is unattainable. Despite these differences, critical links have been made between health and human rights, supported by the WHO and through a number of international declarations. The World Health Organisation (WHO) gave forward a number of recommendations as minimum standards for palliative care, as expected by the

international community⁸. These include that countries should have a national palliative care policy, ensure training and education of health care professionals, promote public awareness, ensure the availability of morphine and ensure that minimum standards of palliative care are progressively developed⁸. Within these recommendations provision is made for low, medium and high resource settings, with home-based care featuring in all of these resource settings, but where in the low resource setting, home-based care is the only available option for palliative care delivery. A number of international statements by the palliative care community have helped to establish palliative care as a “human right”. Conscious of the unfolding tragedy of HIV/AIDS, the inadequate care of patients with cancer and the poor response from governments throughout the African continent, the Cape Town Declaration, made certain propositions⁹. Apart from stipulating that appropriate drugs be available, education programmes be established at all levels and that palliative care should be provided at all levels, it was proposed that palliative care is a right of every adult and child with a life-limiting disease. This was supported and echoed by the Korea Declaration that emerged from the 2nd Global Summit of National Hospice and Palliative Care Associations in 2005¹⁰. In this declaration there was a call for governments to attend to a number of issues pertaining to palliative care, but it was also clearly stated that governments must “make access to hospice and palliative care a human right”. Even though there may be different interpretations of this “human right” and different arguments about the practical implementation thereof⁷, it is clear that the delivery of palliative care has become a non-negotiable expectation and right to those in need of it. Apart from this, caring for the most vulnerable group of people, those dying of a life-threatening disease, reflects on the moral and ethical fibre of a community and society in general⁵. Thus, even in the face of limited resources, we, as health care professionals and this government, have no option but to deliver palliative care to those in need.

The need for palliative care:

This contrasts strongly with what has been happening with mortality and life expectancy in South Africa over the past number of years, as will be shown by the following reported data. In October 2008, the report “Mortality and causes of death in South Africa, 2006”, was published by Statistics South Africa, giving information on the number of people dying from different causes according to death notification forms¹¹. What was astounding is that this

report showed a massive rise of 91% in the number of registered deaths between 1997 and 2006. In the age group 25 to 49 years, the rise was an unprecedented 170% and in 1997 this age group accounted for 29% of all deaths, but in 2006 for 42% of the number of deaths. It has been calculated that population growth could account for about 10% of this increase¹², but this influence can be removed by looking at death rates per 100 000 people. Statistics South Africa provided another report called "Adult mortality (age 15-64) based on death notification data in South Africa: 1997-2004", which showed that the death rate among men aged 30-39 more than doubled, while for women aged 25-34 it more than quadrupled¹¹. According to researchers of the Medical Research Council, the number of deaths attributed to HIV, is a massive underestimate, as the majority of deaths due to HIV is misclassified. Opportunistic infections, like tuberculosis and pneumonia, are often given as cause of death on death notifications, while HIV/ AIDS is not recorded as cause¹². A report published by the Burden of Disease Research Unit of the Medical Research Council of South Africa called "Initial burden of disease estimates for South Africa, 2000", estimated that of 556 585 deaths, 30% was caused by HIV/AIDS and 37% by non-communicable diseases¹³. The World Health Organisation estimated that HIV is responsible for 52% of deaths in South Africa, based on 2002 data¹⁴. It has been reported by the Medical Research Council that AIDS killed around 336 000 people in South Africa between mid-2005 and mid-2006 and UNAIDS/WHO estimates that AIDS claimed 350 000 lives in 2007, almost 1000 per day¹¹. This group of people with HIV/AIDS, dying from "misclassified causes", are all in need of palliative care. Even on child mortality, the available data and statistics appear to be unreliable, but all indications are that child mortality in South Africa is far too high for a middle income country and that mortality has been rising¹⁵, indicating a large group of children in need of palliative care. All of these facts are reflected in a life expectancy of 52,4 years for males and 58,5 years for females and an average life expectancy of 55,2 years¹³. The question arises: "what kind of care are these people getting in terms of managing these life-threatening conditions and helping them to face death?"

Burden of disease:

HIV: All of the above then indicate the devastation of the HIV pandemic and underline the massive need for care of the dying. South Africa has the very doubtful honour of being the country with the highest number of infections in the world¹⁶ and South Africa's burden of

disease due to sexually transmitted infections is currently one of the largest in the world, where 98% of this burden was due to HIV in 2000¹⁷. Even though it appears that the epidemic is in the process of reaching a plateau and where there has been a decrease in the percentage of young pregnant women (15 to 24 years) found to be infected with HIV, suggesting a decline in the number of new infections¹⁶, mortality figures as reported above will remain for now. The change in this burden over the next 10 years will depend on prevention strategies introduced and the coverage given to those in need of highly active antiretroviral treatment (HAART)¹⁷. The South African Business Coalition on HIV/AIDS expressed scepticism at the aims expressed in the national Strategic Plan for HAIDS and STIs (2007-2011) to provide HAART to 80% of the people progressing to AIDS by 2011. At these discussions the estimated 500 000 new infections per annum and the very slow implementation of the National Strategic Plan on HIV/AIDS and Sexually Transmitted Diseases of the government, have been identified as problems¹⁸. "The treatment gap" which shows the difference between the number of patients who are receiving highly active antiretroviral treatment and those who are in need of it, has been published in the past, but less attention has been given to the number of new patients who become in need of treatment every year¹⁹. It has been reported that 640 000 patients developed indications for HAART in 2006 and that a similar number of patients will become eligible every year for treatment over the next decade. Only 100 000 patients, of the more than 600 000 in need of treatment, were started during 2006, indicating that the treatment gap will not be closed if a different approach is not followed for implementing the treatment programme in the future. The World Health Organisation latest estimate is that 460 000 people were receiving antiretroviral treatment at the end of 2007, which was then only 28% of those in need of treatment²⁰. Apart from this, a further concern is a one billion rand shortfall in funding on the government's public sector antiretroviral treatment programme²¹. All of the above information, points to a huge number of people who are expected to die of HIV/ AIDS in the coming years, most of them in need of terminal care, and the introduction of this kind of care earlier in the disease trajectory!

Cancer: Apart from the impact of HIV/AIDS on mortality statistics, there is a growing concern about a huge imminent increase in the number of patients with cancer in Africa²². At present, there are annually 600 000 deaths in Africa due to cancer²³. It is estimated that

by 2020 there will be 15 million new cases of cancer every year worldwide. Of these 70% will be in developing countries, with African countries accounting for over a million new cases annually. These countries are least able to cope with this because of limited cancer care services and limited funding to tackle the problem²². Because of the lack of basic infrastructure and resources, cancer screening and early diagnosis and treatment, do not take place and people with cancer present with late stage disease, when palliation is the only treatment option. It is estimated that a third of the deaths in Africa from cancer are potentially preventable²³. In 2007, at a meeting in London attended by the Ministries of Health of twenty African countries, leading oncologists from around the world, representatives of major national and international health care and cancer-related charities and organisations, the London Declaration of Cancer Control was issued. This aimed at raising awareness of the magnitude of the cancer burden in Africa and was a call for immediate action to bring comprehensive cancer care to Africa. This builds on previous declarations like the Cape Town Declaration on Cancer Control in Africa which was adopted in December 2006, as part of the International Atomic Energy Agency's Nobel Peace Prize Special Event on Cancer Control in Africa. The aim was to raise awareness of the looming cancer problem in Africa; for commitment from governments to initiate and support comprehensive cancer control programmes; for reliable cancer data to be kept by countries to help plan these programmes and also to raise public awareness about cancer, the risk factors and the importance of prevention²⁴. What is also high-lighted is the need for cancer treatment of which palliative care forms an integral part and the desperate need for training of healthcare professionals due to the lack of human resources in cancer care. The reality of the situation in Africa is that until such time as comprehensive and sustainable cancer care programmes are in place and taking effect, people with cancer will be stigmatised, often facing an inescapable and painful death, with palliative care the only treatment option, if they are lucky to receive that at all.

Chronic disease: On another front, the serious health threat of chronic disease, has had a huge impact on the well-being of the world's population over the past thirty years, to the extent that it is called the "new pandemic of the 21st century"²⁵. In many countries there is an epidemiological transition from infectious to non-communicable disease, but in sub-Saharan Africa infections are not decreasing, while at the same time there is an increase in

non-communicable diseases as people adopt a more Western lifestyle. This gives rise to a double disease burden in countries least able to afford it. The HIV epidemic has made predictions about the impact of non-communicable disease on health, uncertain, but data shows that the prevalence of diabetes and hypertension has increased markedly in urban areas over the past 5 – 10 years²⁶. The projection from the Global Burden of Disease study is that by the year 2020, the overall burden due to non-communicable disease in sub-Saharan Africa, will increase to between 26% and 34%. This increasing burden of non-communicable diseases (NCD) like cardiovascular disease, diabetes, cancer and chronic respiratory conditions, will threaten to overwhelm health services that are already overstretched²⁷, impacting on the whole health service delivery. Diabetes is a good example. The World Health Organisation estimated that in 2005, 1,1 million people died of diabetes and its complications, 80% of the deaths occurred in low and middle-income countries and diabetes deaths will increase by more than 50% in the next 10 years²⁸. There are competing priorities because of the burden of the HIV epidemic, management of tuberculosis and malaria and the need for provision of primary health care in areas neglected in the past. This results in very little recognition being given to the magnitude of the burden of non-communicable disease in South Africa, which was responsible for 41% of the reported mortality in 1996²⁹. It is estimated that in 1996, 487 people died per day due to non-communicable disease and that this figure will rise to 563 people dying per day in 2010. Provision for the prevention, early detection and cost-effective management of non-communicable disease, are generally inadequate, resulting in chronic disease being poorly diagnosed and managed. Interventions aimed at identifying, managing and preventing risk factors for non-communicable disease, need time to take effect²⁵ and therefore it is expected to have an ongoing impact on mortality in the next 10 to 20 years.

Considering all of the above, it is clear that there will be a huge need for the palliative care of patients with life-threatening disease in sub-Saharan Africa, but also in particular in South Africa, in the years to come. This poses the question of how well prepared we are to meet this need and who is going to face of this daunting task, ensuring our patients a “good” death to the best of our ability?

Implementation of palliative care:

In an effort to meet this overwhelming demand for end-of-life care, palliative care in South Africa is going through an exciting phase of development in spite of serious restrictions in terms of both finances and human resources. The first palliative care services in South Africa were delivered by the hospices, which were established in the early 80's along the lines of the United Kingdom model³⁰. Hospices in South Africa are non-governmental organisations that are registered as charities, relying on community support for both finances and staffing purposes and are not receiving government funding³⁰. Doctors, social workers and spiritual counsellors provide their services on a voluntary basis. Since the inception of the Hospice and Palliative Care Association of South Africa (HPCA) in 1987, excellent work has been done in the development of professional palliative care standards and the implementation thereof in the hospices³⁰. Through the mission of the HPCA "to promote quality in life, dignity in death and support in bereavement for all living with a life-threatening illness by supporting member hospices and partner organisations"³¹, much has been achieved to spread the palliative care message, especially to educate and inform the public and health care professionals of the role of palliative care in the health care system as an active and total form of care for the patient and family. It also helped to shift palliative care from being only cancer care to involve the thousands of patients with HIV in need of care as well. Apart from this, the HPCA believes that palliative care should be an integral part of every health care professional's training and therefore, initially, palliative care training occurred in the hospices³². This resulted in the HPCA being involved in developing a community caregiver training programme and establishing an Integrated Community-based Home Care programme, adapting it to the needs of the community³². Palliative nurse training in the hospices has been happening for a long time and the Hospice Association of South Africa certificate course in palliative nursing is accredited by the South African Nursing Council. Through these training programmes much has been achieved to establish a stronger palliative care base, but as the need for palliative care is growing, so is the need for training.

Training of clinicians:

Family physicians are playing an integral role in primary care, and primary care has a vital role in delivering palliative care³³. Patients with life-threatening diseases spend the majority of the last year of their life at home, under the care of their own family physician³⁴. No wonder that in the United Kingdom where palliative care is a speciality, but where there is a tendency to move away from primary care, there is a plea for recognition of the contributions the physicians with a primary care / general practice background, are able to make to the speciality and palliative care in general. The central role primary care professionals play in optimising palliative care is recognised, but they often lack the necessary resources and training to do this effectively³³. This then emphasises the need for family physicians to be trained, facilitated and supported in palliative care. In South African health care there is a focus on cure, resulting in health care professionals turning away from patients for whom cure is no longer possible³⁵, even more so stressing the need for training in the face of the existing and growing palliative care burden. Most of the hospices rely on the voluntary services of general practitioners interested in palliative care, but who are at the same time running busy general practices and most of whom have never received any formal training in palliative care. The University of Cape Town (UCT) was able to fill this urgent need by recognising an opportunity to create an educational programme to assist African doctors in developing the palliative care skills needed to manage the ever-increasing number of patients with life-threatening diseases, who need physical, psycho-social and spiritual care. In 2000, UCT created an honorary lecturer post in palliative care and approved a distance-learning curriculum developed in conjunction with the Palliative Medicine Division of the University of Wales, College of Medicine in Cardiff. The first post-graduate students registered in 2001³⁵. The curriculum was developed and adapted to accommodate the unique South African/African needs with reference to cultural diversity, HIV/AIDS and the need for palliative care for children. Two programmes are offered at UCT: a postgraduate Diploma in Palliative Medicine and a Masters of Philosophy in Palliative Medicine, aiming to provide doctors with understanding of the principles and practice of modern palliative care and with the long term goal of broadening palliative care services within communities where they are most needed. These programmes have attracted a

number of doctors nationally and internationally, such as doctors involved in hospice work, general practitioners, oncologists, paediatricians and doctors from other disciplines. Another encouraging development is that all medical schools have integrated palliative medicine into undergraduate curricula and the Departments of Family Medicine have incorporated a module on palliative medicine into the curriculum of the M.Fam.Med. degree³⁶. The National Department of Health has also appointed a working group with the aim of integrating palliative care into the formal health care system, with training and personnel as a priority for 2006. The measures taken to improve the quality of palliative care services through training is impressive, but it is also true that all possible resources need to be mobilised and developed to meet the overwhelming demand. This poses the question then of what the role of the family physician will be in helping to meet the need.

Rationale for the study:

As already stated, all of the above developments took place over the past number of years, with the result that the majority of practising family physicians in South Africa, have not received any formal palliative care training³⁵, even though caring for those with life-threatening disease, will be part of their daily practice. In the World Health Organisation's World Health Report 2008, primary health care is again lauded as the solution to reorienting health systems that are struggling and threatened to be overwhelmed by aging populations, pandemics and chronic disease³⁷. Primary care has a vital role in delivering palliative care³³ and when patients are being cared for at home, the family physicians are the primary and often the only medical professionals, caring for them in the last months and weeks of their lives³⁸. It is also known that patients spend the majority of the last year of their lives at home under the care of their own family physician³⁴, even though many of these patients end up dying in hospital³³. Palliative medicine is a holistic approach to caring for and managing life-threatening illnesses where all bodily systems may be involved, where psycho-social and spiritual needs arise as well and where the impact on family and carers is taken into account. Family physicians are ideally equipped to care for most terminally ill patients, as their training imparts the skills and knowledge to treat common problems associated with every system of the body and the name "family physician", indicates that they play that role not only for their patients, but also for the families involved.

In the light of this huge expected and already present palliative care burden, the role of the family physician is of great importance as already stated above. This then poses the question of how well these practising physicians are equipped to make the necessary contribution to palliative care, to relieve the suffering of terminally ill patients and if they are willing to shoulder this responsibility.

University of Cape Town

LITERATURE REVIEW

A review of the literature was done by using the Pubmed / Medline and Ovid databases. The search words used initially were: palliative care / palliative medicine and family physicians / general practitioners. This was further refined by using “knowledge / attitudes / belief / practice” respectively as add on search words. A number of palliative care / palliative medicine journals are available online through the Health Sciences Library portal and they were searched systematically: Journal of Palliative Medicine, Palliative Medicine, Journal of Pain and Symptom Management specifically.

Review article: Systematic review relating to General Practitioners and palliative care:

A very good overview article by Mitchell was found, relating to palliative care and GPs in general. In a systematic review of all available literature, asking the question: “How well do general practitioners deliver palliative care?” a wide variety of information was found, reflecting the knowledge, attitude, belief and practices of general practitioners towards palliative care. The aim was to examine the nature of care in palliative medicine by general practitioners, the perceptions of general practitioners (GPs) and others of that kind of care, the adequacy of palliative care training and issues relating to accessibility of GPs to palliative care patients. A literature search in Medline / Pubmed, using key words: general or family practitioner, palliative, cancer and death, yielded 135 relevant articles, reporting research into an aspect of GP performance of palliative care, including bereavement care or education in palliative care³⁹. **Clinical exposure:** It was found that GPs’ exposure to palliative care was limited, but consistent: Australian GPs see five to six terminally ill patients per year on average, UK GPs referred a mean of 5,5 terminally ill patients for specialist palliative care services and Canadian family physicians managing one patient dying at home per year³⁹. This limited exposure probably makes it hard to stay abreast with new developments in the discipline. **Benefits to patients with GP involvement:** GPs see a number of benefits to their involvement in palliative care as palliative care aligns with the principles of family practice, ensures continuity of care and their knowledge of the patient and family environment is an

advantage This indicates a positive attitude to palliative care in general. **Performance:** How well GPs deliver palliative care and their performance in delivering optimal symptom and pain control, is questioned in view of a UK survey that reported that a high percentage of patients dying at home still experience pain³⁹. A survey of relatives of patients, who died at home, has shown that there is room for improvement in the area of symptom control. Patients showed a preference to be managed by their own GP and to die at home. They rated the care given by GPs as well and the causes of dissatisfaction centred round communication problems. A positive attitude towards GPs was observed, when they were easily accessible and available for appointments and visits and took the time to communicate well. There appears to be a discrepancy between pain and symptom control as reported by GPs and carers and the actual situation as experienced by patients, underlining the role perception plays in the observation of patient symptoms. The proportion of GPs reporting difficulty in managing pain has decreased over the past years due to improved education. **GP knowledge and clinical practice:** The GP's knowledge of symptom control strategies was found to be sound amongst East Anglia family practitioners, the majority of UK GPs use opioids appropriately and GPs in an Australian community hospice conformed well to best practice guide-lines³⁹. Knowledge in other countries was not so good, with the knowledge of Canadian Family Medicine residents poor, but improving with education, Greek GPs had poor pain management knowledge and Belgian GPs' knowledge was shown to be poor and not as good as their perceived levels of knowledge. GPs in countries with well-developed palliative care services probably have the skills needed to deliver basic palliative care. As far as symptom identification is concerned, GP identification of the most common symptoms experienced by patients did not correlate with the actual symptoms suffered by patients. In terminally ill patients with colorectal cancer, there was only moderate correlation between patient symptoms and the GP's perception of the presence of these symptoms. GPs often failed to identify those symptoms that are difficult to manage and those less commonly seen. In bereavement care, USA family physicians and UK GPs recognised the importance of the bereavement period and the importance of contact with the relatives of deceased patients. Very few practitioners have received formal training in bereavement care and also report that they often grieve the death of patients and experience guilt feelings at such a death. **Confidence in management:** In several countries a positive attitude towards palliative care was shown, seeing it as a

special part of their role, considering it as important, rewarding and satisfying³⁹. They see themselves as part of a team of carers, often acting as the coordinator. Managing psychological distress and symptoms, GPs found to be the hardest to cope with, but the longer the time spent in general practice, the more comfortable they felt in managing palliative care patients: the more experienced, the higher the level of involvement in palliative care. **Training:** Training of doctors in palliative care was not extensive. A high percentage reported no training in communication skills and bereavement care and even in vocational training for general practice. Palliative care training was inadequate, although confidence in palliative care is reported to be improving during the GP registrar year in the UK³⁹. Education delivered in standard ways, may meet the needs of interested doctors, but not necessarily the broader palliative care community. **Accessibility:** Patient accessibility to the GP is an indicator of good GP performance in palliative care and in a UK study more than three quarters of urban GPs were willing to make themselves available after hours to care for dying patients, but many GPs were not informing after-hours services of the details of their terminally ill patients³⁹. There was general dissatisfaction with the level of specialist support available after hours. This systematic review article gives a wide and general indication of GPs' attitude, knowledge and practice in palliative care.

A number of studies, which will be discussed in the following paragraphs, were done in different countries and also different geographical areas, reflecting factors influencing palliative care in the practices of family physicians⁴⁰: perceived competence in providing palliative care⁴¹, roles, knowledge and priorities in the provision of palliative care by London GPs⁴², the care of cancer patients by urban family physicians⁴³, attitudes toward palliative care in rural Australia⁴⁴, perceived tasks and barriers in daily practice of palliative care in the Netherlands⁴⁵, attitudes of Danish doctors towards palliative care⁴⁶, perceived obstacles to the delivery of primary palliative care⁴⁷, doctor's understanding of palliative care⁴⁸ and the preferences of patients and doctors in preparing for the end of life⁴⁹. All of these studies give an indication of attitude, knowledge, belief and practice of family physicians towards palliative care, although some more indirectly^{46, 47, 49}. Only one reference on South Africa was found of a small study that was done on GPs in Bloemfontein⁴⁸.

The international situation:

Canada:

In a Canadian study by Brown et al. aimed at exploring the factors that influence family physicians' decisions to practise palliative care, and their motivations and obstacles and also personal and subjective experiences in practising palliative care, there was a strong feeling of participants that GPs must be responsible for the palliative care of their patients and a strong belief that the philosophy of palliative care needs to be extended and integrated throughout medical practice and medical education.⁴⁰ This study had some limitations which influenced the validity in that it was a very small sample size, with only eleven participants using semi-structured in-depth interviews, a very restricted geographical area and the majority of participants were already involved in palliative care. It was found that the common philosophy of palliative care was shaped by education, professional and personal experiences. Within this philosophy there was an acceptance of death, a strong focus on care of the whole person, the importance of compassion, communication and teamwork being stressed. Events in their own professional careers left them feeling inadequate in caring for their dying patients and that was a stimulus to become more involved and better educated as undergraduate training in palliative care was very limited. Participants found palliative care to be rewarding. It enhances clinical skills and they were learning to be patient centred and also growing in their communication skills. In spite of the participants giving this very positive attitude, they themselves felt that family physicians in general were not taking up their palliative care responsibilities because of inadequate remuneration, lack of time, lack of comfort with death, lack of knowledge, lack of structure in palliative care and reluctance to do house calls, indicating negative factors within the wider community of family physicians.

United States of America:

The frequency and perceived competence in providing palliative care to terminally ill patients was tested by Farber et al. in a randomly chosen sample of a thousand primary care physicians across the United States of America⁴¹. A cross-sectional mail survey was done through an anonymous questionnaire consisting of two sections gathering information on

how frequently palliative care was provided to terminally ill patients and their families and how proficient they felt themselves to be in providing different aspects of palliative care, including discussing advanced directives, managing physical symptoms, addressing relationships of patients, giving hope, breaking bad news to patients and their families, managing psychological and spiritual needs and addressing economical problems of terminal disease. Of the different activities mentioned above, respondents felt that they performed most of the activities in an excellent or good manner, but perceived themselves to be less confident on spiritual care and managing the economic aspects of terminal care. Perceived competence was higher for those physicians who had more of an interest in palliative care and performed the different activities more frequently, and also for those who had received previous training in palliative care. Only 36% of respondents reported having received any form of palliative care training, indicating a need to increase frequency of delivering palliative care activities and also to increase perceived competence. On average the respondents reported managing 19 terminally ill patients per year. Even though the sample size for this study was fairly extensive, the response rate was only 48%, introducing possible non-respondent bias, with the authors suspecting that the non-respondents were either not providing palliative care or not interested in the topic. The data was also self-reports and the actual behaviours of the respondents were not assessed, thus influencing the validity of the study as perceived competence does not always correspond with reality

United Kingdom:

A postal survey of London GPs was done by Burt et al. investigating their attitudes towards the provision of palliative care and their view on specialist palliative care services⁴². A postal questionnaire was sent to all eligible GPs in five primary care trusts in London, a total of 620 doctors. The response rate was 57%, with female GPs over represented in the response group and GPs from solo practices under-represented. Most GPs (65%), reported that they are currently providing palliative care to their patients, with the majority caring for 1 to 3 patients, with 22% caring for four to six and 15% more than seven patients. The majority of GPs (72%) agreed or strongly agreed that palliative care was a central part of their role, although this was less true for single-handed GPs. It was found that those GPs who had more partners in a practice, who were at that time involved in palliative care, who had

received palliative care training and those who had more years experience in GP practice, felt more strongly about their involvement in palliative care and they were less likely to hand over care to specialist services. There appears to be tension in relationships between GPs and district nurses. Poor communication and heavy workloads may lead to misunderstandings and breakdown in co-ordination of care and the actual practice of palliative care. A lack of knowledge about the available specialist services was shown, and there is a need for good relationships between family physicians and specialists, to fill the present gaps in knowledge. These findings are the views of GPs in inner city practices, limiting the possibility of generalization of the results. Furthermore older and GPs working alone were under represented amongst the respondents, affecting the validity of the findings. The authors felt that the respondents might represent those GPs more concerned about and committed to palliative care.

The Netherlands:

With the view to further development of palliative care services, a qualitative study was done by Groot et al. to identify GPs' opinion of their task in palliative care and the barriers they encounter in delivering this service. All GPs from a district were invited to participate (n > 200), but in the end 22 GPs participated in 3 focus groups through interviews using an interview guide with open-ended questions⁴⁵. Every GP perceived working in palliative care as responsible, at times difficult, but most rewarding as it combines all the different aspects of patient care. They perceived their own tasks and performance as caring for patients and their families, using communication, cooperation skills and medical knowledge. There was uncertainty about whether to delegate certain tasks to others, the concern being that continuity of care would suffer. Participants stated very clearly that competence in palliative care is essential, but reported a number of areas where they felt they lacked competence. They identified a lack of knowledge in symptom and symptom control, lack in certain practical skills and lack of knowledge about the resources and advanced treatments available in palliative care. Emotions identified revolved around frustrations concerning their coordinating and care-giving roles and frustrations with other professionals who are not doing enough to ensure proper care. Not having enough time to fulfil their role, was a trigger to emotions. Communication problems were identified as a barrier in care-giving, at the level of patient / family communication and also communication with other health care

professionals. They felt that the role of the GP was not acknowledged and therefore there was poor collaboration with other professionals. The practice of palliative care was hindered because of organisational delays and constant changes in the organization of care. There were weaknesses in this study in that GPs with limited experience in palliative care were under-represented and the participants were mostly from group practices. In another study in the Netherlands, concerning the perceived barriers to the delivery of palliative care, communication difficulties, especially with family members, were high-lighted, but almost a quarter acknowledged that the time and attention they gave to family members was insufficient. They were feeling positive about their knowledge of treatment options, but lacked knowledge about home-care equipment. More years of experience, education and multi-disciplinary involvement resulted in less perceived barriers in this study ⁴⁶. Although there were 320 respondents (response rate 62,3%), the results were limited in that they display only the perspectives of GPs, while professionals from other disciplines, patients and families may experience other barriers. The authors also felt that they may have collected a group of GPs with a special interest in palliative care, which will influence the generalizability of the results.

Denmark:

The attitude of Danish doctors, both hospital doctors and GPs, to palliative care was tested by Vejlggaard et al. in a rural county, where there were very limited palliative care services⁴⁷. This was done through a self-administered postal questionnaire. The response rate was 76%. Again the majority agreed that doctors have a role to play in reducing suffering, but only 30% of respondents found palliative care rewarding and 10% preferred to hand care to others. More GPs than hospital doctors found palliative care rewarding and were less likely to hand palliative care to others than hospital doctors. They felt that they lacked confidence due to insufficient training. They also felt that education and better support would improve their attitudes, and that they needed to develop a better understanding of the caring aspect of their work. The strength of this study is the good response rate, that both primary and hospital care was covered and that these findings may well reflect the attitude of doctors as a whole because Denmark is a small country,

South Africa:

Only one article was found that related to the South African situation, a short report on a study on the attitudes and practices towards palliative care of Bloemfontein general practitioners and medical officers⁴⁸. From the responses it was clear that very few of these doctors received any training in palliative care, either at undergraduate, postgraduate or vocational level and that most felt that there was a real need for such training. A positive attitude towards palliative care was reflected in the willingness of most to give home palliative care and realising the need for the involvement of the family in care. There was significant weakness in this study in that the response rate was very low and the authors reported that it was clear from the responses to the questions on knowledge, that these questions were not well formulated and that those results were not commented on.

Urban / rural perspective:

Canada / urban perspective:

In another pilot study by Dworkind et al. amongst an urban population of family physicians in Canada, the interest of community-based family physicians in caring for cancer patients was assessed⁴³. An anonymous questionnaire was mailed to 106 family physicians who were all involved with a Department of Family Medicine of a teaching hospital. The questions were about the number of cancer and palliative care patients seen in their practices the previous month, their use of community cancer resources, their interest in proposed continued medical education (CME), the preferred methods of CME and whether they were interested in accepting new cancer patients. The response rate was 68,8% and no significant differences were found between responders and non-responders in terms of demographics. The family physicians followed a mean of 3,2 palliative care patients in the previous month, but almost 30% managed no palliative care patients in that time. In this group of physicians, community support services for palliative care were seldom used, possibly because they were unaware if these services, dissatisfied with the services or that they were not familiar with the multi-disciplinary approach in palliative care. A very positive finding in this study was the interest shown in improving knowledge, attitudes and skills, especially in symptom control and pain management. The method preferred for CME was mostly through case-studies, followed by lectures and seminars. Even though most of these physicians were following a small number of palliative care patients, very few were prepared to take more

referrals of patients in need of end-of-life care. As this was a pilot study in a restricted location, the results may not be representative of perceptions and attitudes elsewhere in North America and the possibility of generalization of the results may be restricted.

Australia / rural perspective:

The aim in this study by O'Connor et al. was to explore the attitudes of rural general practitioners towards the philosophy and provision of palliative care, with the research questions focusing on attitudes to palliative care, what the factors contributing to these attitudes in a rural setting were and what the perceived barriers to the delivery of palliative care⁴⁴ were. A qualitative in-depth research design was used, with the participants the 10 registered GPs within a specific rural setting and in-depth interviews were conducted with each. Open-ended questions were used, touching on emotions, beliefs and experiences in delivering palliative care. The overall attitude towards palliative care was positive, but a number of themes emerged that were found to be challenging. Maintaining the quality of life of patients was identified as the key aspect by participants. Pain and symptom control was the most challenging area for GPs, but they acknowledged the holistic approach in palliative care and that quality of life included all the other areas of care. Discussing spiritual issues, as well as talking about psycho-social and emotional problems, was reported as being difficult and further training in these areas was deemed essential. The importance of continuity of care was underlined, and participants felt more comfortable in managing palliative care patients with whom they were familiar. Emotional issues were perceived as a source of stress for GPs, even to the extent that their own mental health may suffer if they became too involved with patients. Because of the lack of support for rural GPs, they felt more exposed to this danger, as patients and families were relying more on the GP for emotional support. The awareness of their own mortality was also raised, as they were dealing with terminally ill patients, but age and experience were found to be factors influencing emotional awareness positively. The attitude towards a team approach in palliative care was very positive, as the participants felt that other team members helped them to cope with emotions, time-management and the delivery of palliative care. There was a feeling that specialist palliative care services were over-emphasised, undermining the role of the GP, that they are not receiving recognition and that this was an actual barrier to palliative care delivery by GPs. There seemed to be a resistance to further palliative care

training amongst these participants, but they will value support by telephone when faced with palliative care difficulties. Better financial support for service delivery will also create a more positive attitude and a feeling of being supported. Participants viewed palliative care delivery positively, but a need for support was identified in dealing with stress. Communication, lack of funding and the increase in specialist services threatening the role of the GP, were perceived as barriers. The generalizability of the results is restricted as it was only a small group of participants interviewed in a specific location.

Clinical management:

Palliative care for patients with chronic disease:

To deliver palliative care to those patients dying from chronic disease has its own challenges. In discussions done in a UK study by Hanratty et al., in 7 focus groups, consisting of general practitioners and specialists from different disciplines, doctors' understanding of palliative care given to patients dying from cardiac failure, was assessed⁴⁹. There was strong support for the holistic approach in palliative care and palliative care as an ideal model of care. The concepts of managing cardiac failure and giving palliative care even from the time of diagnosis have not been embraced. Although the GPs were more open to talk about death, they also felt that their communication skills could improve and they seemed to be more receptive to the concepts of palliative care than the doctors from other specialities involved in the study. The focus groups were arranged along specialities, the number of people involved was small and from one region, restricting the generalizability of the conclusions drawn.

Staging patients as palliative:

Whether doctors introduce palliative care early in the disease trajectory, gives information about how well they grasp the palliative care concept. It was found in a study in the UK by Farquhar et al. that compared hospital doctors and GP's view on palliative status, that GPs showed a greater reluctance to define patients as palliative. In 20% of the cases of patients with colon and lung cancer, deemed by hospital doctors to be for palliation, the GPs disagreed⁵⁰. Hospital doctors and GPs may interpret "palliative" differently, with differences in knowledge and understanding of palliative care. The strength of these findings can be questioned as the data used came from consultation and discharge letters, where the GPs

had only limited information and not the full hospital notes, and this study applied only to lung and colon cancer patients.

Specific palliative care topics / actions also give general information on knowledge, attitude, belief and practice towards palliative care. These topics include: the management of symptoms of dying patients⁵¹, controlling cancer pain in primary care and prescription habits^{52, 53}, attitude and knowledge about cancer pain^{54, 55}, artificial hydration⁵⁶, perspectives regarding palliative radiotherapy⁵⁷, communication^{58, 59, 60}, place of death / dying at home⁶¹, end-of-life decision making^{62, 63}, hospice referrals and attitudes towards hospice care^{64,65, 66, 67}. These will be discussed in the following paragraphs.

Symptom management:

As palliative care becomes more of a specialised discipline with even in-patient specialist services available, there is a possibility that GPs, who will be supervising the care of about 90% of people dying at home, may lose valuable skills needed to deliver palliative care⁵¹. In a study in Australia by Mitchell, the medical care provided to terminally ill patients in an in-patient palliative care unit was compared with the gold standard of literature based practice guidelines. On a chart audit of the first 20 patients in the unit, each new symptom or symptom that changed was recorded and this was examined to see if an attempt was made to identify the direct cause and how it was managed. A total of 135 symptoms were recorded, diagnosis was attempted in 70% of these, and 90% of treatments offered were according to guidelines. The symptoms for which least attempts were made to diagnose a cause were constipation, nausea, anorexia and pain of unspecified origin. Although this was a small study and therefore the results cannot be extrapolated to care given at home, there is some evidence that GPs are able to provide care according to guidelines in an in-patient setting.

Pain management:

A UK study by Barclay et al. was aimed at determining the knowledge base amongst GPs concerning issues about pain control by examining their own prescribing habits and knowledge of palliative care⁵². From a postal questionnaire sent to 450 GPs in East Anglia - response rate 73,3% - it was found that all were aware of the WHO pain ladder. They were

familiar with commonly encountered pain problems, but less familiar with drug options in less common problems and with syringe drivers. There was no reluctance to start strong opioids, 84% were correct in managing breakthrough pain and almost everybody was using anti-inflammatory drugs in bone pain. About half of the respondents gave anti-emetics and laxatives with opioids, but only 68% made the correct conversion from oral to subcutaneous morphine. In total incorrect responses were given by 31% of the respondents, so there is room for improvement, but the majority of GPs prove to have good knowledge of cancer pain management. Even though the response rate was high, there was response bias in that respondents were more likely to come from training practices and to have been more recently qualified. The study was also restricted in that it assessed only the self-report of GPs.

In contrast, in a report on the use of opioids and pain management in cancer in Italy by Welshman, a completely different picture was painted⁵³. Morphine consumption is an indicator of improved pain management strategies and indirectly shows whether there is a palliative care service available. There is a huge difference in morphine consumption between the United Kingdom and Italy, even though these countries have very similar health care systems, indicating a huge need for education of both the public and the physicians in Italy. In a palliative care service in Rome it was found that GPs had difficulty in evaluating pain. They lacked knowledge in analgesic potency, dosages and routes of administration, where “as needed” prescriptions were common and poor patient information was given regarding the prescribed drugs. Far too much attention was given to addiction and dependency, as well as possible side-effects. Inadequate knowledge concerning the legislation relating to opioid use, caused apprehension to prescribing morphine as a safe alternative for controlling chronic pain.

A mailed survey was posted to 537 family physicians in West Virginia to assess their current knowledge and attitudes about pain⁵⁴. More than 80% were happy to prescribe high doses of opioids for cancer pain, but the same percentage of the respondents were reluctant to use opioids in chronic non-malignant pain and reported frustration with those patients in terms of managing their pain. About 90% of the respondents believed that their patients were happy with their pain management and 75% felt that patients do not have to suffer as much pain as possible before proper pain management is instituted. As far as knowledge is

concerned there were a significant number of wrong answers about the use of fentanyl patches, prescribing laxatives, respiratory depression and the use of pain killers in the elderly. Interestingly, almost two thirds of respondents felt that formal training did not prepare them adequately for effective pain management. This study had a relatively small sample size, response rate was low and non response bias was not assessed, affecting the generalizability and interpretation of the results.

Bauwens et al. used a questionnaire to assess health care workers in Flanders, concerning cancer pain management and misconceptions leading to under-treatment⁵⁵. The majority of the participants believed that cancer pain can be relieved effectively, but that pain is often undertreated. Misconceptions about drug dependence were common, and it was believed that a request from the patient for an increased dosage of opioids was due to tolerance and not disease progression. There was limited knowledge about morphine and its side-effects. The majority of participants were aware of the subjective nature of pain and that the patient is the best judge of the intensity of pain, but only 55% felt that maximum dosages of analgesics must be used. GPs were a minority group within the participants, which makes it difficult to extrapolate these findings to GPs in Flanders as a whole.

Artificial hydration:

In two separate surveys for doctors and nurses in Japan, attitudes towards artificial hydration for terminally ill patients were assessed by Miyashita et al.⁵⁶. Regarding the factors relating to the provision of artificial hydration it was found in Japan that those carers less involved with terminal care were more likely to use it. They believed that artificial hydration is needed for effective symptom control and it is the minimum standard of care. In the physician group, 595 doctors responded (53% response rate), the majority working in oncology and palliative care centres. The belief that artificial hydration alleviates the sensation of thirst, was held by 43% of the doctors (mostly oncologists), not understanding the importance of mouth care. Doctors working in palliative care centres had a better understanding of the fact that withholding hydration was beneficial to palliate certain symptoms like nausea, cough and dyspnea. These findings cannot be extrapolated to the general population of doctors as the participants were working in oncology and palliative

care and general attitudes may be confounded by answers relating to specific scenarios used in the questionnaire, thus limiting generalizability.

Palliative radiotherapy:

A study was conducted in Ontario by Samant et al. to evaluate the knowledge and perspectives of family physicians towards palliative radiotherapy, as it was found that there was an under-use and under-referral of palliative care patients for palliative radiotherapy⁵⁷ by family physicians attending the greatest majority of these patients. There was a 57% response rate to the mailed questionnaire and although 80% of the respondents were involved in providing palliative care to their patients, only 56% had referred patients for palliative radiotherapy in the past. Only 50% of the respondents felt that radiotherapy was effective for painful bone metastases, but far fewer felt that radiotherapy was indicated for spinal cord compression, brain metastases, hemoptysis and hematuria. This is to be expected as less than 20% of the respondents had any training in radiation oncology. From this study it seems that there is a direct relationship between the level of knowledge of the indications for palliative radiotherapy and the referral for such. Although the intent of this study was not to perform a complete evaluation of radiotherapy knowledge, it did give some good indications of such knowledge.

Communication:

Some interesting findings were made when the attitudes and beliefs of palliative care physicians regarding communication with terminally ill patients were compared in three different physician populations in French speaking Europe, Canada and South America⁵⁸. All doctors felt that their patients should be informed of their terminal status, although most European and South American doctors stated that most of their patients were not aware of their diagnosis. They also believed that only a small minority of patients would want to know of the terminal stage of their illness. The Canadians held a different view on this point. There was consensus that an informed patient had a better quality of life and that joint decision-making was better. It was clear that there were cultural differences, but also differences in approach to communication in the different regions. These findings were amongst palliative care physicians and cannot be extrapolated to primary care physicians, but are of interest.

Bruera et al. used a questionnaire, exploring doctors' experiences with end-of-life care, their attitudes towards palliative care and their personal and professional backgrounds. The attitudes and practices around disclosure of prognosis to terminally ill patients amongst French doctors were studied⁵⁹. With a response rate of 59%, half of the respondents were GPs. More than 16% of these GPs felt uncomfortable with palliative care patients. Half of them will only disclose prognosis "if it is really necessary or if the patient explicitly asks for it" and only a small number will opt for systematic disclosure without the patient's request; one out of eight opted for concealment. Of the individual patients described by the respondents, 44,5% were informed by the physician of their prognosis, but 19,2% were never informed because the physician opted for concealment. In this study doctor-patient communication was studied from a very narrow perspective, as only physician attitudes were studied retrospectively, which was a limitation to validity. It also seems that attitudes and practices were not matched perfectly. From this study it appears that in a French context, patient request is a strong prerequisite for disclosure.

Literature indicates that spirituality is important to most patients and that the majority of primary care physicians believe that they should listen to and support their patients on spiritual and existential concerns, but this seldom happens in practice⁶⁰. Studies done in the past around communication regarding spiritual concerns, had severe limitations because of low response rates, research conducted in areas where there was a high percentage of Christian doctors and patients, limiting interpretations. Thus the practice of spiritual care in health remains unclear. In this study by Holmes et al., a questionnaire, where spirituality related to religious and existential concerns, was sent to 72 patients selected according to certain criteria, and a different questionnaire was sent to a group of 77 primary care physicians in a particular health setting⁶⁰. Almost two thirds of the patients wanted their doctor to address their spiritual concerns, but of these 60% did not want to have a spiritual discussion. Of the total, only 11% had ever been asked by their GP if they would like to discuss spiritual matters. Low percentages of patients had ever been asked about the importance of spirituality to them, asked if they were part of a spiritual community or offered a chaplaincy referral. More than two thirds of the physicians felt that it was important to address patient's spiritual concerns and yet, almost the same number indicated that they never ask their seriously ill patients about a chaplaincy referral. When

asked about the reasons for not giving spiritual care, the majority cited lack of time, some felt incompetent and others felt that it was not part of their job. The findings in this study were consistent with previous research, indicating that patients' spiritual needs are not addressed adequately by their physicians.

Place of death / dying at home.

To ascertain the views and attitudes of physicians in Spain towards patients dying at home, a questionnaire was sent to all doctors caring for patients at home in a particular health district by Porta et al.⁶¹. In spite of a high level of participation in this study, indicating a real interest in the subject, difficulties in attaining the main objectives of palliative care were voiced. A third of the doctors felt that the degree of comfort experienced by cancer patients at home was inadequate and even more felt critical of the quality of the attention given to the families. Older professionals were less critical, but urban doctors were three times more critical of the support given to families than their rural counterparts were. In this particular group of respondents, there was a surprisingly high number, almost two thirds, who felt that patients should not be informed about their diagnosis. Yet, home was considered to be the best place for terminally ill patients to die. This was a well structured study but had some limitations in that it was a self-administered questionnaire whose reliability and validity was not assessed, and the study population was relatively small.

End-of-life decision-making:

End-of-life decisions (ELDs) have become very complex, involving legal, ethical, medical and psychosocial issues⁶² and involve withholding or withdrawing potentially life-prolonging treatments, alleviating pain and other symptoms with the possibility of shortening life. In some countries this also involves euthanasia, physician assisted suicide and measures aimed at ending life without explicit request from patients^{62, 63}. Information regarding ELDs, may give an indication of attitudes toward palliative care. A questionnaire already used in other countries, was sent by Seale to a thousand GPs and a thousand specialists in the UK, to estimate the frequency of ELDs in medical practice⁶². There was a very low incidence of all three forms of doctor-assisted dying (euthanasia, physician assisted death and ending life without an explicit request from the patient) in the UK, which was significantly lower than in Belgium and the Netherlands, but non-treatment decisions were more common in the UK

than in other European countries. This may indicate medical decision-making strongly influenced by a palliative care philosophy. In a survey by Lofmark et al. of physicians, including GPs, in Australia and six European countries, attitude, behaviour and practices concerning end-of-life care and ELDs, were assessed and compared⁶³. In all the countries, especially in Australia, Belgium, Denmark and the Netherlands, the majority of physicians intensify symptom control in situations where they know it may hasten death. The majority of physicians in Italy will never increase the dosage of medication to the level where it can hasten death. Intentionally hastening death at the request of the patient was most common in the Netherlands. Those physicians who had palliative care training and who attended more than five terminally ill patients in the past 12 months were more inclined to make end-of-life decisions. Experience in ELDs can be associated with the opportunities the physician has to make ELDs and also the attitude towards the philosophy of life, like patient autonomy and preservation of life. Legislation and medical guidelines are also reflected in ELDs. The strength of this study lies in that the same methodology was used in all the countries, which made it possible to compare the different countries. This was a retrospective study and therefore recall bias possibly affected validity.

Hospice: attitudes and referrals by family physicians:

A number of studies were found relating to the attitudes of physicians towards hospices and their use of and referrals to these facilities of terminal care^{64, 65, 66, 67}. In America there has been a growth in the use of hospice services, although it is still underutilized; therefore the need to examine the physicians' attitude towards, as well as knowledge and perceptions of benefits and barriers to hospice care⁶⁴. A questionnaire developed by Ogle et al. based on a literature review, was mailed to all physicians, of whom more than half were family physicians, in a Midwestern city, with a 72% response rate. All of the positive attitudes tested in the questionnaire, were endorsed by at least 80% of the respondents, strongly agreeing with the value of hospice as a treatment option for terminally ill patients and the effectiveness of such treatment. Respondents felt comfortable with their role in facilitating hospice referrals for patients and families and also felt that the doctor is the most appropriate person to fulfil that role. Nearly all physicians knew that hospice care is available for all terminally ill patients and not only cancer patients. To the other knowledge questions there was a significant number of "uncertain" responses and lack of knowledge

related more to uncertainty. In this study physician barriers identified were negligible and the most common barrier experienced by physicians, was resistance from the patient and family to hospice care. This study was again limited in that it was conducted in a single medical community and the behaviours are self reported, which may not be the actual practice.

In a study by Shipman et al. in England to compare GPs, use of and attitudes towards specialist palliative care services in different geographical areas, the results have shown a wide variation in the way palliative care is provided in the primary care sector and the ways in which specialist hospice care is utilised⁶⁵. Of the 63 GPs interviewed, 9 GPs rarely made use of specialist palliative care services because they felt that they had sufficient palliative care knowledge, and because of poor communication within the multi-disciplinary team about the care of the patient or disagreement about medication. The majority of GPs used these palliative care services as a resource through open and proper communication channels, thus gaining access to proper support. A small number of GPs worked with palliative care services as part of an extended team. Seven GPs from the inner city area handed over all palliative care to the specialist services. Encouraging is the fact that the greatest number of GPs wanted to take responsibility for the palliative care of their patients and through communication and according to preference of the patient and the skill of the primary care team, access specialist services as needed.

In a survey by Brickner et al. which was given to physicians, including GPs, working in a Health Maintenance Organisation to determine their attitudes towards hospice services, their knowledge of these services and diagnosis appropriate for referral and the perceived barriers to referral, all felt that hospice care added quality to the lives of terminally ill patients, but 75% felt that it was an underutilized service⁶⁶. The majority were making referrals when appropriate, felt adequately trained to discuss a patient's death, but preferred hospice to be involved in these discussions. The self-assessed knowledge was tested against the actual knowledge where respondents had to correctly identify eight appropriate diagnoses for hospice referral. Only 18% of respondents answered this correctly. Almost a quarter of the respondents felt inadequately trained for palliative care. The most common reason for referral was the belief that hospice staff can more effectively guide the patient and family during the terminal phase, indicating that physicians are having

difficulty in confronting the patient's death. Pain control problems are the second most common reason for referral. Of the barriers identified, correctly predicting the time until death was the most common. Lack of time to discuss the issues relating to death and dying and a concern that patients may perceive a hospice referral as a sign of loss of hope, were the other barriers found. There was a very clear discordance found in this study between perceived and actual knowledge, underlining the need for training.

In interviews with hospice experts across America aimed at understanding the relationship between physicians and hospices and physicians' attitudes towards hospice, it became clear that late referral of terminally ill patients seems to be a problem⁶⁷. It seems that physicians with a multidisciplinary approach to medicine are more likely to do hospice referrals⁶⁶. Those with palliative care training and continuing medical education that includes end-of-life issues are more likely to refer to hospice. Communicating with and being supported by physicians from the hospices, were all enablers in promoting referrals. All of these influence attitudes, knowledge and practice around hospice referrals.

Assessing the family physician's role in terminal care as perceived by patients and carers:

By reviewing information from patients and carers, insight can be gained into the attitudes, practices and knowledge of GPs concerning palliative care. In a study to get a clearer picture of how cancer patients experience the care they received from family physicians, 400 cancer patients sampled from the Cancer registry in Manitoba, were surveyed through a postal questionnaire by Sisler et al.⁶⁸. Patients who described their GPs as "very involved" were more satisfied with the speed of diagnosis, but 30% of the respondents felt their diagnosis should have been made earlier. Patients felt that the aspects of caring for general medical problems, prompt referrals, taking extra time during consultations and prompt office appointments, were well handled. On the other hand family support and home visits were less frequently provided. According to the patients emotional support was not well provided, which is a concern. This study had some limitations, as younger patients with breast and prostate cancer were over-represented in this sample, the cross-sectional design of the study did not permit causal interpretation and how the patients' needs were communicated was not surveyed either. The experiences of carers concerning the palliative care provided by GPs to their patients indicate a high level of satisfaction, especially for those patients who died in their own home⁶⁹. This is in spite of symptom control not being

good: pain control was not good in 50% of cases and shortness of breath and insomnia were poorly managed in 30% of the patients. This again supports the idea that symptom control by GPs can improve and contrasts with the favourable perception GPs have of the symptom control that they provide. Subjects and their GPs were offered the opportunity to opt out of the study and this may have introduced response bias in a study with a low response rate, affecting validity.

Training in palliative care for family physicians:

Training in palliative care received even at undergraduate level, is an important indicator of the knowledge, attitudes, beliefs and practices of GPs towards palliative care and lack of such training the reason for problems experienced in the actual delivery of such care. An international survey of undergraduate medical education in palliative medicine was done in all Canadian and all United Kingdom medical schools and randomly selected medical schools in the United States and Western Europe by Oneschuck et al⁷⁰. The United Kingdom medical schools have the highest percentage of mandatory or required rotations in palliative care, but in contrast, this was strikingly low in Canada, United States and Western Europe. More than half of all universities have formal lectures in palliative care, but the time spent was low, only 4 to 6 hours on average. Most palliative care training in the United Kingdom is done in the hospice setting, while in acute care hospital teams in Canada, United States and Western Europe. Evaluation is mostly done through case reports and presentations and there is minimal inclusion of palliative medicine in formal examinations. This survey was limited in that it was 3 years old and curriculums may have changed since, but the overall conclusion was that medical students are not well trained in palliative care and that education should be a priority for medical schools.

In a review article of the current literature by Charlton et al., there was a recurrent theme of reporting on serious deficiencies of training of physicians in caring for patients at the end of life and that this has been neglected during medical school training and the residency years⁷¹. In a review of the literature, it was found that in 1994 very limited time was given to formal training in palliative care, with the same finding in a Canadian study in 2001, resulting in junior doctors not being confident in caring for the dying, with breaking bad news and dealing with grief of relatives. In a study published on a survey done in Maryland,

America, amongst internal medicine house staff, a lack of knowledge was found and respondents felt uneasy in dealing with dying patients. The majority of oncology staff (92%) in a hospital in Brisbane expressed the need for palliative care training, the training deficit arising from undergraduate level. In the developing world, in countries like India and Chile, the situation was even worse. An improvement in the inclusion of palliative care in undergraduate training in the United Kingdom has been reported, but the emphasis that medical schools give to this important subject is still minimal. In a global systematic review done in 2004, it was found that teaching in palliative care was fragmented and focused on acquiring knowledge and skills rather than attitudes. All of these point towards the need for a strong focus on postgraduate training.

A number of studies were done in the United Kingdom to evaluate the palliative care training GPs received during their training years as students, junior hospital doctors, GP trainees and as GP registrars^{72, 73, 74}. A postal survey of 450 GPs in East Anglia done by Barclay et al., with a response rate of 86%, assessed the palliative care training received during the four career stages mentioned above, in the five key areas of palliative care of pain control, control of other symptoms, communication skills, bereavement care and the use of syringe drivers⁷². Data from this study showed that palliative care training of medical students focused mostly on symptom control, with little training in communication skills and bereavement care. Although training in palliative care of clinical students has become more common, there is room for improvement, as many students feel themselves inadequately trained in palliative care, especially in breaking bad news and coping with their own emotions. Training during junior hospital years appears to be almost absent, but the greatest majority of GP trainees reported receiving training in all of the five areas, with most training received during the GP registrar years. This study assessed exposure to training, but the adequacy in preparing GPs to care for terminally ill patients, was not assessed. A very similar questionnaire study was done in Wales also by Barclay et al., also assessing the training received during the four career stages mentioned above and also in the five palliative care areas mentioned⁷³. The findings in this study were very similar to the findings in the study done in East Anglia, probably pointing to the generalizability of the data⁷². A country-wide postal survey by Low et al., of GP registrars explored their satisfaction with palliative care training, their perceived confidence in applying their knowledge, specifically

their knowledge of cancer related pain⁷⁴. The majority have received training in pain and symptom control, but most did not receive training in bereavement care and syringe driver use. The result being that they were feeling moderately confident in symptom control and communication, less so in the use of syringe drivers and not confident in bereavement care. The data from this study did show an improvement from previous studies, but again underlined the need for the development of better palliative care education for GP registrars.

Most studies done on education in palliative care, focused on the training and education given, with less studies done to determine the educational needs of family physicians^{75, 76}. In a study in the United Kingdom by Shipman et al. the educational preferences of inner-city, urban and rural GPs were surveyed⁷⁵. Confidence in symptom control, attitudes towards specialist palliative care services and ease of access to palliative care information were also assessed. On the preferred topics for palliative care education, about half of the respondents wanted to receive education in symptom control for non-cancer patients. The other topics for which they most requested training were advice on using analgesics other than opioids, controlling nausea and vomiting, prescribing opioid, breaking bad news, syringe driver use and counselling and communication skills. In spite of this, half of the respondents felt confident in symptom control and did not have a problem with access to palliative care information. These findings do not reflect the GPs' competence in palliative care, but only their perceived educational needs in palliative care training.

In a Delphi survey by Dowling et al. in which 32 Irish GPs participated, 77% indicated that they need further education in palliative care and syringe driver use, and newer treatments in pain and other symptom control were identified⁷⁶. The correct use of opiates in terminal care was a particular concern for these GPs and also the use of multiple drugs and the knowledge of drug interactions and adverse effects. Irish GPs also wanted further training in counselling and communication skills. Of the participants, 60% have participated in palliative care courses, indicating that Irish GPs view palliative care as an important part of primary care. The preferred method of training was through case studies and practical workshops and also for this training to be multi-disciplinary. The findings of this survey were validated by a separate group of 18 GPs, therefore it can be stated that these findings are likely to represent the views of Irish GPs at large.

Conclusion:

This literature review provides a wide perspective on a range of articles that either directly or indirectly reflects on the knowledge, attitudes, beliefs and practices of GPs in relation to palliative care and will be referred to again. It is clear from the literature review that in most of the developed countries, the role of GPs in primary palliative care is acknowledged and encouraged. The GPs are willing to fulfil their role, but in even the countries where palliative care is a speciality, there is room for improvement on different aspects of clinical management. What is of particular concern is that apart from one study from South Africa, no other literature on this topic was found relating to sub-Saharan Africa. This is an aspect to which attention will have to be given in future, as primary care physicians have a huge role to play in health service delivery in Africa. It is also important to note that the literature spans a considerable time. Situations, service delivery, training, populations, needs etc. may have changed and be different from what was reported in the literature reviewed above.

METHOD

STUDY DESIGN:

This is a descriptive, cross-sectional KABP study.

AIM

To determine the knowledge, attitudes, beliefs and practices of general practitioners practising in the Boland and northern suburbs of Cape Town, towards palliative care.

OBJECTIVES:

1. To assess the palliative care knowledge and practices of practising general practitioners.
2. To ascertain what the attitudes and beliefs of general practitioners are towards palliative care.
3. To determine if general practitioners are equipped for the delivery of holistic primary palliative care effectively and with confidence.

STUDY POPULATION:

The defined population is a group of general practitioners who are at present practising family medicine within the health sub-districts of the northern suburbs of Cape Town, Bellville, Durbanville and Brackenfell, and the Boland towns of Stellenbosch, Paarl, Wellington, Franschhoek, Rawsonville, Worcester, Ceres, Tulbagh, Porterville and Malmesbury.

Sampling: The names of all the general practitioners practising in the mentioned area, were obtained from the medical pages of the Telkom Telephone Directory 2007 / 2008 and from the MED pages Healthcare Directory 021 2008. A total of 242 names were identified in this way and they were approached to be involved in the study.

DATA COLLECTION TOOL:

This is a self-administered questionnaire that was developed through a process of firstly reviewing the questions. The questions decided on were constructed with guidance from a handbook⁷⁷, examples of questionnaires used in other studies^{15,17,25,28}, own experience in general practice and in consultation with my supervisor. This was followed by a piloting process, recognising that there is little control over the quality of the data and completion of the questionnaire⁷⁷. The variables to be measured are mentioned in the heading of the questionnaire. This was followed by demographic information: gender, age, demographic area of practice, year of qualification and years in practice.

A total of twenty questions were decided on, recognising that these are too few questions to accurately reflect the data on the four different variables namely, knowledge, attitude, belief and practice. As the response rate to postal questionnaires is low⁷⁷, this was done to keep the time needed to complete the questionnaire within reasonable limits. Keeping it brief was an attempt to strengthen the potential response rate. Questions were constructed in such a way that the different questions measure knowledge, attitude, beliefs and practice. The first number of questions measure attitude and questions that respondents may perceive as threatening, were used towards the middle and end of the questionnaire. Effort was made to keep questions simple, concise and specific⁷⁷, avoiding double negatives. This was done to ensure that one question was asked at a time and to develop face validity. This was further developed through a piloting process to improve content validity. Closed questions were used, where respondents had to answer either "yes" or "no", to encourage quicker and more standardised data collection, even though it could inhibit response⁷⁷ and create difficulties in interpretation of data, as will be discussed in the section on limitations.

The pilot process was done to refine the questionnaire by testing the content validity and reliability and also to change questions according to the guidelines mentioned above. This process started by the questionnaire being sent to 6 colleagues who are palliative care trained, of whom only one responded, in spite of follow-up. Consequently the questionnaire was tested on a group of 15 palliative care nurses who were doing a palliative care course. This was followed by the questionnaire being sent to members of the Department of Family Medicine at the University of Cape Town for comment. During this process different

changes were made to the initial construction of questions. Questions were changed to be more direct for example from: “when morphine has been titrated to high doses, caution is called for as respiratory depression is a danger” to “morphine cannot be titrated to high doses, because of the danger of respiratory depression”. All negative statements were removed to avoid having double negatives as the answer options are “yes / no”. The wording of some questions was too open and had to be changed to make the question closed, for example “I may initiate giving intravenous fluids to a terminally ill patient” was changed to “initiating intravenous fluids to a terminally ill patient”. During the piloting process ambiguity was removed from questions and it was ensured that only one question was asked at a time. This piloting process was undertaken to strengthen the validity and precision of the questionnaire.

The final questionnaire is attached as Appendix 2. The different variables were tested as follows: knowledge – questions 5, 6, 7, 9, 10 and 13; attitude – questions 1, 2, 18 and 20; belief – questions 2, 4, 8 and 19 and practice -- questions 11, 12, 14, 15, 16 and 17.

DATA COLLECTION PROCESS

A KABP (knowledge / attitude / belief / practice) survey was done. These surveys are based on the theory that health-related behaviour, in this case palliative care, is influenced by knowledge, as well as by attitude and beliefs of the subject⁷⁷ and therefore have some limitations. Responses can be influenced by recall and what is perceived to be the correct answer, so it is a report of knowledge, attitude, belief and practice that is measured and not the actual knowledge, attitude, belief and practice. The data collection was done through a self-administered questionnaire that was posted, with a return envelope included, to all the identified general practitioners. Also included in the envelope, was a cover letter, giving personal information on the researcher, explaining the background, reason, aim, objectives of the study, stating the variables to be tested and giving reassurances around confidentiality and protection of identity of the participants (See appendix 1). Three weeks after the questionnaires were mailed non-respondents were contacted either personally or through their receptionists, requesting return of the questionnaire. A further three weeks later, contact was again made with non-respondents per telephone, encouraging attention to the questionnaire.

DATA ANALYSIS

Data was entered in Microsoft Excel and analysis done in Stata Version 11 (StataCorp. 2009. Stata: Release11. Statistical Software. College Station, TX: StataCorp LP). The chi-squared test will be applied for categorical variables and the t-test for numerical variables. Statistical level of significance will be at $p < 0.05$. Responses to questions will be arranged according to bar charts. The above-mentioned statistical processes will be applied to explore if there are significant differences between gender, years in practice and age.

ETHICAL CONSIDERATIONS:

This project received approval from the University of Cape Town Research Ethics Committee (REC REF: 190 / 2008).

The nature and the purpose of this study was disclosed and explained to participants in a cover letter that accompanied the postal questionnaire and can be viewed as Appendix 1 to this study. There is minimal risk involved for participants, apart from feeling exposed by being uncertain about the answers to certain of the questions. However, there may be benefit involved in those areas in which training may be needed that will be highlighted. No written consent was obtained as completing a postal questionnaire is totally voluntary and by doing that, consent is given by implication. Routine follow-up was done for non-respondents, but apart from that, no pressure was applied to non-responders to complete the questionnaire. Questionnaires were numbered for follow-up purposes only, but confidentiality and anonymity were guaranteed as only the researcher and a secretary had access to the names of the participants. In the dissemination of the information, no reference will be made to any particular participant or town.

RESULTS

Demographics: The response rate was 34,7%. Of the total of 242 questionnaires sent, 84 were returned. Of the 84 respondents 65 (77,4%) were male and 19 (22,6%) were female with the location of practices being 29 (34,5%) rural and 55 (65,5%) of the GPs practising in urban practices. The mean age of the respondents was 49,9 years (standard deviation 8,6) with the average age of the rural doctors 52,1 years and the average age of the urban GPs 48,8 years. In both rural and urban locations, the average age for male doctors was more than the age for female colleagues, the difference being 5,5 years for rural GPs and 8,9 years for urban GPs. On average (mean) the respondents have spent 21,9 years in practice (standard deviation 8,9), the average for rural doctors 23,1 years and 21,3 years for urban doctors. The male respondents in rural and urban locations, have spent 23,8 and 23,7 years in practice on average respectively and their female counterparts 19,3 and 14,9 years.

See table 1.

Table 1:

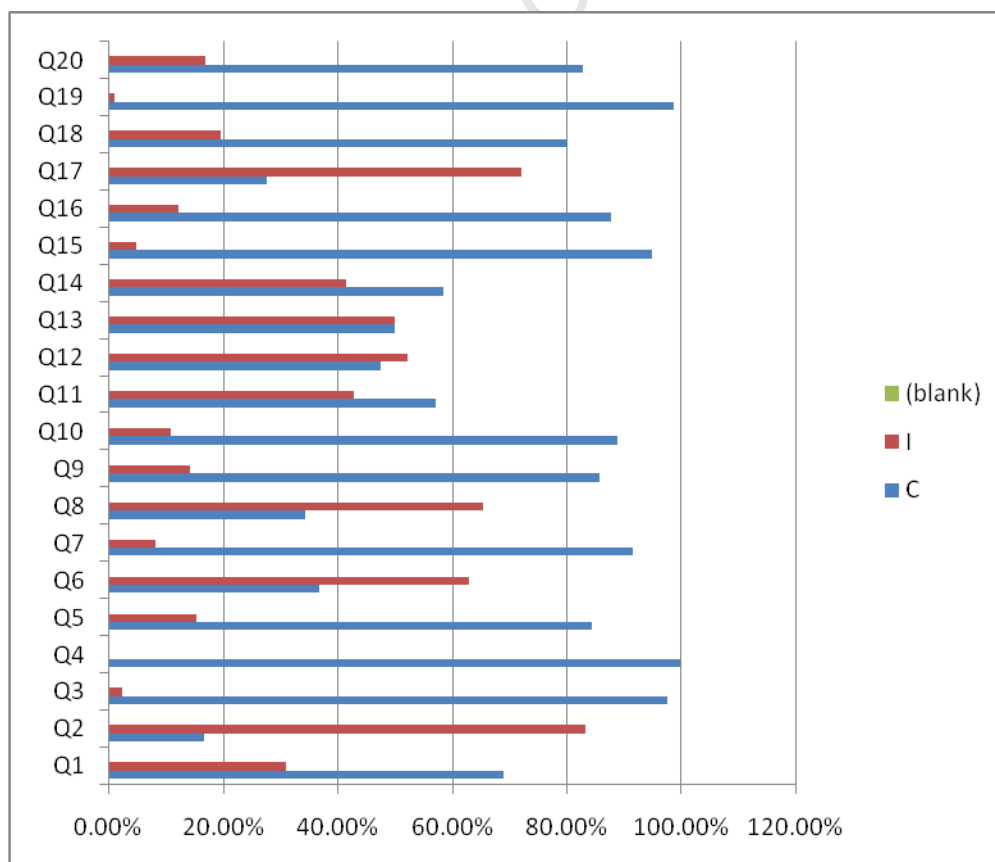
Row Labels	Average Years	Average Age	Max Age	Min Age
RURAL	23.1	52.1	65	40
FEMALE	19.3	47.5	52	40
MALE	23.8	53.0	65	38
URBAN	21.3	48.8	59	38
FEMALE	14.9	42.4	53	28
MALE	23.7	51.3	69	30
Grand Total	21.9	49.9	59	38

Concerning the number of palliative care patients managed in a given year the respondents reported as follows: 19 GPs said that they managed between 0 and 5 patients, 25 doctors managed 5 to 10 patients in a year, 17 GPs 10 to 15 patients and 21 GPs cared for more than 15 patients in a year. Two respondents did not answer the question.

Overall responses to questionnaire: Of all the 20 questions answered per questionnaire by the 84 respondents, the desired answers were given to 69,45% of the questions while to 30,55% of the questions inappropriate responses were given.

To 10 of the questions, more than 80% of the respondents gave the desired answer. Of the inappropriate answers given, 83,33% of the respondents answered as such to Question 2 on the holistic approach in palliative care, and 72,29% to Question 17, on the use of anti-emetics in the palliative care drug regime. To Questions 6 on the holistic approach in pain management and 8 on the role of the GP in the palliative care team, 63,10% and 65,48% respectively of the answers were not the desired response and to a further 2 questions (Questions 12 on the use of intravenous fluids and 13 on the use of syringe drivers) 52,38% and 50,00% did not give the preferred responses. These results are further demonstrated in Bar chart 1. The topics of the different questions and the results of the individual questions will be reported on in the different sections.

Bar Chart 1:

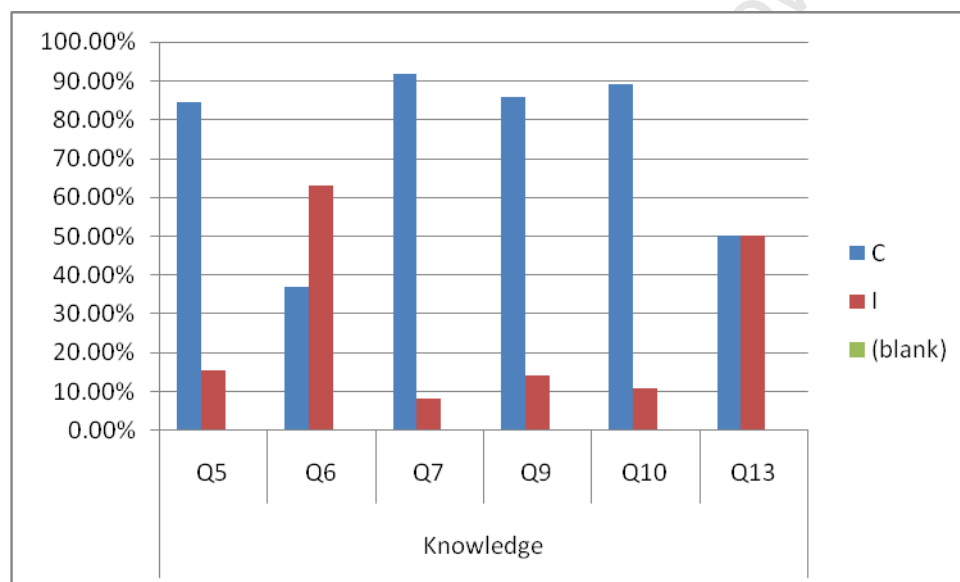


C = Correct (Blue) (Desired response) I = Incorrect (Red)

Knowledge:

Six questions were used to test knowledge in the questionnaire: Questions 5, 6, 7, 9, 10 and 13. In total, the desired answers were given on 72,91% of the questions, and 27,09% not. Question 6, relating to the holistic approach to pain management, an inappropriate answer was given by 63,10% of the participants. Only half of the respondents answered question 13, relating to syringe driver use, positively. On all of the other four knowledge questions, more than 80% desired answers were received. These questions touched on morphine use and respiratory depression, danger of addiction to morphine, emergencies in palliative care and spinal cord compression in terminally ill patients.

Bar chart 2: C= Correct (desired response): Blue / I= Incorrect: Red

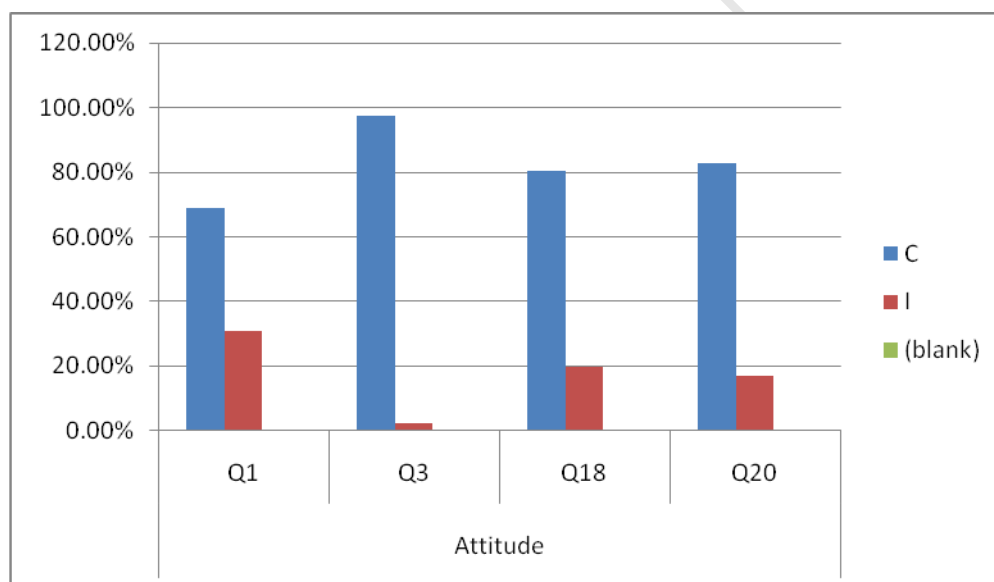


No difference was found in the number of positive and negative answers between doctors practising in urban areas (72,56% correct) and rural areas (73,56% correct). No significant difference was found in the level of knowledge when applied to gender ($P=0.241$), with 73,45% positive answers from female participants and 72,75% positive answers from male participants. In terms of number of palliative care patients managed in a year: in the category 0 to 5 patients, 78,76% desired answers were received, 5 to 10 patients group had 67,11% positive answers, the 10 to 15 patients group had 69,61% desired answers and in the more than 15 patients category, 76,19%. For the number of years in practice, the following percentages of desired answers were received: nil to 10 years 78,76%, 11 to 20

years 68,65%, 21 to 30 years 77,97%, 31 to 40 years 60% and 41 to 50 years 72,22%. A two sample t-test used for this data did not show any significant difference ($P=0.2441$).

Attitude:

To the four questions exploring attitude, viz. questions 1, 3, 18 and 20, a high percentage of preferred responses were received, 82,48% “correct” and 17,52% “incorrect”. To question 1, 69,05% of the respondents reflected a positive attitude towards palliative care in general. To question 3, there was an overwhelming positive attitude towards the importance of the patient’s involvement in decision-making by 97,62% of the respondents. On average 80,25% of the respondents, reacted positively to their own emotions around the management of palliative care patients and 82,93 % were open for further palliative care training. See bar chart 3: C= Correct (desired response) Blue / I= Incorrect: Red



In the case of differences in attitude by gender, the female respondents fared slightly better than their male counterparts, with 85,33% and 81,64% desired answers respectively. No statistical significant difference was found when tested for gender (P -values: 0.836 for question 1, 0.979 for question 3, 0.101 for question 18 and 0.530 for question 20). In terms of location of practice, rural GPs gave 83,33% preferred answers and urban GPs 82,03%.

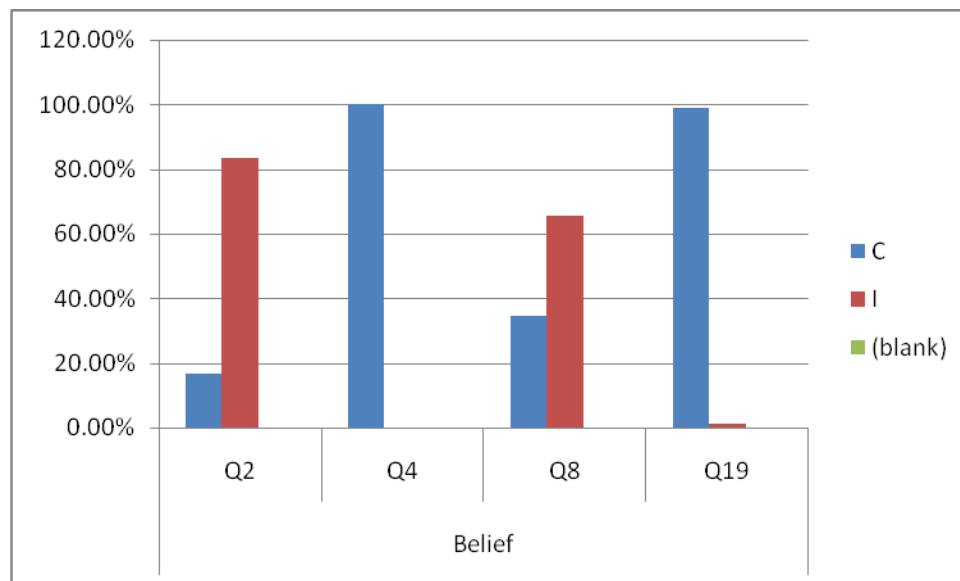
In the category number of palliative patients managed per year, the GPs indicating that they managed 5 to 10 patients per year, fared the best with 90,91% positive answers. Of the group seeing 0 to 5 terminally-ill patients per year 82,67% desired answers were received

and the group 10 to 15 patients gave 80,88% positive answers. The GPs managing more than 15 palliative care patients in a year had only 75,31% desired answers and those who did not indicate the number of patients seen in a year, fared the worst with 75,31% positive answers and almost 25% less appropriate responses. The group of GPs with 11 to 20 years of GP practice experience, had the highest number of desired answers – 89,52%, and the GPs who did not indicate the years in practice, had 100% desired responses. Of the other 'years in practice' groups the results were as follows: 1 to 10 years – 77,27% desired responses; 21 to 30 years – 78%; 31 to 40 years – 78,95% and 41 to 50 years – 75%. No significant difference was found when age (≤ 50 and > 50) was applied to the different responses, except for question 18. This question deals with the management of emotional issues around palliative care and a preference for counsellors to deal with it. A significant difference was found ($P=0.002$) with 32,5% of the older age group indicating that they prefer not to deal with emotional issues in comparison with only 5,2% of respondents in the younger age group.

Belief:

In answering the four questions on belief, a huge variation was found in the desired answers. For the four questions, 62,39% gave the preferred response and 37,61% not. Question 2 on the holistic view of presenting symptoms in palliative care, 83,33% of respondents did not give the desired response. All respondents answered question 4 about the involvement of the family in decision-making, positively. To question 8, on the position of the GP in the multi-disciplinary team, 65,48% less appropriate answers were received. To question 19 about their involvement in bereavement care, 98,80% of the respondents were positive about their role. See bar chart 4.

Bar chart 4: Key: C= Correct (desired response) Blue / I= Incorrect: Red

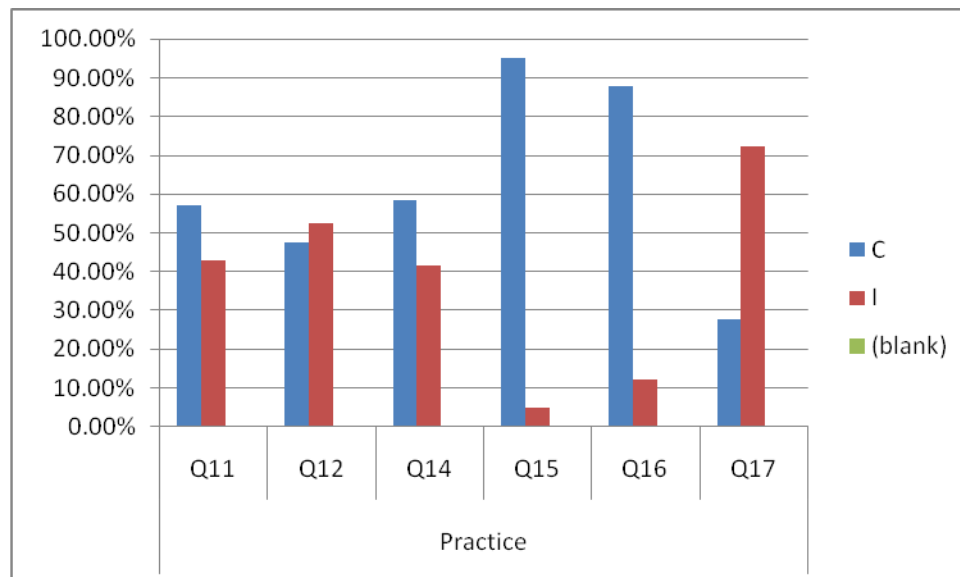


In terms of location of practice very similar results were found on the belief questions with 62,61% preferred answers by rural doctors and 62,27% preferred responses by urban doctors. The female respondents gave 64,47% “correct” answers and their male counterparts 61,78%, with no significant difference ($P=0.451$, $P=0.339$, $P=0.594$ for questions 2,8 and 19). No significant difference was found in the number of desired answers between the different groups in terms of number of palliative care patients cared for per year: 0 to 5 patients 59,21%, 5 to 10 patients 63%, 10 to 15 patients 63,24% and more than 15 patients, 61,45% desired answers respectively. The doctors with 41 to 50 years of practice experience had 50% undesired responses and with the same result for doctors who did not indicate their years in practice. The number of preferred answers received for the other groups were very similar: 62,50% for 1 to 10 years in practice, 65,32% for 11 to 20 years, 61,59% for 21 to 30 years and 60% for 31 to 40 years in practice respectively. Again no statistical significant difference was found for years in practice or for the number of palliative care patients managed per year.

Practice:

Six questions were used to assess practice, with significant variation between desired and not desired answers on the different questions. See bar chart 5.

Bar chart 5: C= Correct (Desired response): Blue / I= Incorrect: Red



To question 17 that reflects on the routine use of anti-emetics when prescribing in palliative care, 72,29% of the respondents will not use anti-emetics routinely, which is not a preferred practice. A high percentage of desired answers were given to questions 15 and 16 - 95% and 87,80% respectively - where question 15 deals with ethical principles in palliative care question 16 with the use of laxatives with opioid analgesia. To questions 11, 12 and 14 there were almost an equal number of preferred and not preferred responses. Question 11 on the combination of different opioids, had 57,14% desired answers. To question 12 that dealt with the use of intravenous fluids in terminally-ill patients, 47,62% of the answers were the preferred response and question 14, on the use of the subcutaneous route as a way of delivering drugs and fluids, 58,54% of the respondents were aware of this route of delivery.

The difference in desired / not desired answers between rural and urban doctors was insignificant with 65,27% correct for rural doctors and 60,57% for urban GPs. There was minimal difference in the answers of female and male respondents, with 61,95% and 62,04% correct answers respectively (P values for the six questions are as follows: 0.825, 0.862, 0.940, 0.914, 0.321 and 0.533) Looking at the number of palliative care patients

managed in a year no pattern was found, with 66,67% appropriate answers for GPs seeing more than 15 patients per year, 5 to 10 patients per year and those who did not give this information. The doctors seeing 0 to 5 patients per year had 55,26% desired responses and those seeing 10 to 15, had 56,57%. Again there was not a significant difference between the different groups for years in practice.

The doctors who did not fill out this information had the highest score here with 83,33% correct answers. GPs with 41 to 50 years practice experience had the lowest score with 55,56% of preferred responses. The percentage of desired answers for the other year groups ranged from 58,38% to 64,71%. No significant statistical difference for ≤ 50 and >50 age groups were found on further statistical analysis.

University of Cape Town

DISCUSSION

The role of the family physicians in caring for their terminally-ill patients is widely accepted, as they are best equipped through their training and long term relationship with patients to offer this kind of care³⁸. Even though palliative care has become a specialist field in many countries, relatively few patients will require specialist care. The majority of palliative care patients will need care from primary medical care professionals who understand the palliative care approach, who have received basic palliative care training and have knowledge about the principles of symptom control⁷⁸. Lloyd-Williams et al. state that across the world most people will spend their last year of life at home, cared for by family physicians, primary care nurses and carers³⁴. This supports the view concerning the importance of the GP's role in end-of-life care. As the GP is in a position to offer continuity of care and where a long term relationship has been built with a patient often over a period of years⁷⁹, he / she will still be the preferred primary caregiver in palliative care. It has also been shown that the persistent involvement of the GP in caring for terminally-ill patients has beneficial consequences for these patients and their families on multiple levels of care⁸⁰.

Demographics:

Of the total number of respondents, 77,4% were male with a much smaller group of female respondents. The percentage of urban practices was much higher at 65,5% with again the rural practices representing a much smaller group, increasing the risk of bias in terms of deductions to be made from this demographic information. The gender distribution in this data corresponds closely to that in other studies^{41, 46, 47, 52, 54} where the study sample came from both urban and rural populations and where postal questionnaires were used to collect data. In some of these studies the number of rural GPs was higher^{46, 47}, but in others it was close to the data obtained in this study⁴¹. The average age of our respondents corresponds well to the age group of the majority of the respondents found in other studies^{47, 52, 54, 61, 65} and so does the average number of years in GP practice^{42, 52, 54}. The similarities of demographic data in this study population to that found in studies in other

countries, may lend some weight to the fact that the respondents in this study may represent a wider community of family physicians. Of the 84 respondents 25 GPs indicated that they managed 5 to 10 palliative care patients in a year, which is the biggest group and corresponds closely to the report in some other studies^{42, 47, 61}. The 21 GPs who reported managing more than 15 palliative care patients in a year, is a high number when compared to data from other studies, and this number of patients was found in only one other study⁴¹. That may put into question the accuracy of this report by the particular respondents or may mean that there are fewer options for patients in the study area in terms of oncologists and hospices.

Even though the female group of GPs was small in comparison with their male counterparts and also the rural doctors against their urban colleagues, no difference was found in the appropriateness of the answers given by these groups. It appears that gender and location do not seem to be relevant factors in giving a desired response to a question. In terms of years in GP practice, no particular pattern was found in the appropriateness of answers. One would expect that more recently qualified doctors have had palliative care education during training or that doctors with longer practical experience would answer a questionnaire better. The number of palliative care patients managed in a year, did not make any significant difference in the ability of the respondents to give the preferred responses to questions and did not reveal any particular pattern. These findings correspond with those found in other studies where age, sex, number of patients and locality of the practice did not make a statistically significant difference in responses from participants^{52, 54, 62}. The study area chosen provided a sample size of potential respondents that was large enough to allow for non-response. This sample area had subgroups in terms of general practitioners being male or female or practising in a rural or urban area. Even though this is not part of the aim and objectives of this study and the sample size may be too small for the different subgroups to yield precise estimates, it may be useful information for this study and also future studies.

Limitations:

Response rate:

The response rate for this postal questionnaire, after the initial mailing and one telephonic reminder and a second reminder in some cases, was a low 34,7%. If the 11 questionnaires which were returned undelivered were to be brought into account, the response rate would have been 36,4%. A review of published GP reports gives a response rate of 61% on average and it is known that response rates for GP questionnaires have been dropping over the last number of years. The response rate in this study is well below average⁸¹. It is suggested that incentives be used to improve response rates, even for inducements to become part of the research process⁸², but none of these approaches were used in this study because that would have meant further costs. It is also reported that written reminders or telephone reminders, as were used in this study, can raise response rates by up to 13%. It is an open question whether inducements as mentioned above, like monetary incentives, would have made any difference to the response rate in this case. It is known that the prominence of the subject surveyed is a strong indicator of the response⁸¹. Other studies have shown that there is a strong correlation between non-response and lack of activity or lack of interest in that particular field⁸¹. The low response rate may then well be an indication of these two factors, meaning that even though GPs are regularly involved in palliative care, as indicated by the number of patients managed in a year, they lack particular interest in palliative care or has not identified it as a particular field of work. In this respect one has to note that the average age of the participants is just below 50 years, meaning that very few of them would have received official training in palliative care as this was only introduced to undergraduate courses recently³⁵. Other studies have shown non-responder GPs to be older, more experienced, often in single practices, more stressed and less well qualified than responders⁸¹. No further survey of non-responders was done in this study which is a weakness.

Bias: A low response rate to a questionnaire increases the risk of bias as respondents usually differ from non-respondents⁸³. Non-response bias depends mostly on two factors, namely the percentage of the sample not responding, which is high in this case, and the extent to which the non-responders differ from the respondents⁸⁴. Non-response bias seems to be a

factor in this study, which weakens the study and results. Another limitation of this study is that the questionnaire is a self-report, making recall bias a possibility, as there was no control over the time taken to answer the questions, or the accuracy of the answers. The sampling was representative of the given study area as a questionnaire was sent to every GP address found in that particular area. As already mentioned, the demographic data in this study was very similar to that found in other studies and even though there is a low response rate with the resultant weaknesses as mentioned, some comparisons may be drawn with data from other studies.

Limitations relating to questionnaire:

In retrospect a number of weaknesses were identified in the questionnaire after data collection. Firstly it needs to be noted that with 4 to 6 questions per KABP, it is difficult to accurately capture the desired information and data. This will be further confounded by a low response rate. The number of questions chosen, namely 20, was an effort to make the questionnaire more time-friendly. This was an effort to improve the potential response rate, as it is known that GPs do poorly on returning postal questionnaires. This was a difficult balance to try to achieve.

The original motivation in choosing yes / no responses, was again an attempt to keep the questionnaire as brief as possible. This again was aimed at attempting to increase the response rate, hoping that by being given a more simplistic questionnaire, GPs might answer more readily. In retrospect one has to recognise that the yes / no responses created some limitations to the data collected. For some of the questions an absolute true / false response is not altogether appropriate. As an example, for questions Q1, Q2, Q3, Q4 the answers would be better described by phrases like “desired response”, “preferred answer” or “most appropriate answer”. The answers are not entirely true or false as a viewpoint or opinion is sought. To other questions a “sometimes” response may be factually more correct than just yes or no. Examples of such questions are questions 11, 12 and 13. Question 15 aimed at exploring whether respondents are familiar with the ethical principles mentioned. The yes / no response options limited the data collected on this particular aspect.

Although I acknowledge the limitations of the questionnaire, much has been learned through this process. Problems around the questionnaire have limited the analysis of the

data and have been obstacles in obtaining a deeper understanding of KABP in this case. This is an initial exploratory study and I would recommend that the yes / no questions be further explored with qualitative work and more detailed questions. A qualitative study where GPs had more freedom to express their views through, for instance, interviews or a different questionnaire may be a better approach if this study was done again.

Attitude:

Of the four different variables tested namely knowledge, attitude, belief and practice, the four questions on attitude were answered the best with 82,48% preferred answers on average. One has to realise that attitude is a very broad concept that involves cognitive information namely thoughts and beliefs, the emotions of the participants involved and their experiences in palliative care⁴⁴, and this cannot be captured in the context of four questions. The high percentage of desired answers reflects an overall positive attitude to aspects of palliative care as represented in the questions. The question on whether managing a terminally ill patient is a positive experience, although challenging, had the lowest number of desired answers in this section, namely 69,05%. Even though the majority of respondents show a positive attitude to caring for the terminally-ill, there is also a good number of GPs who have some reservations and negative feelings about caring for the dying. Those GPs who are positive towards palliative care acknowledge the difficulty and the challenges of the task, but experience it as rewarding⁴⁴ and not as a burden⁴⁵. In certain studies the number of GPs who found palliative care rewarding was as low as 30%, but it has also been proven that education and experience can change attitudes⁴⁶. In other cases, by comparison, this percentage of GPs who see palliative care as central to their work and are willing and eager to fulfil that role to the extent that they are unwilling to hand over care to specialists, may be as high as 72%⁴². This is almost similar to our findings. It was also established that the doctors with this attitude will probably have a number of partners in the practice, have more years of experience as a GP, have received formal palliative care training and will be involved in the provision of palliative care to their own patients⁴². In our results the average number of years in practice overall is 21,9 years, indicating good experience and, according to demographic data, all of the respondents are involved in delivering palliative care. Although most of these GPs would not have received palliative care training and we do not know whether the respondents are in single or group practices,

the first two factors mentioned may be an indication of the reasons for the positive attitude from respondents. The overall low response rate in this study may indicate, as already mentioned, a low interest in palliative care and even a negative attitude amongst the non-respondent group.

A total of 80,25% of the respondents indicated that they are comfortable with emotional issues and that they prefer to deal with those issue themselves. This then underlines the overall positive attitude as reported above, as physicians often report that emotional issues are a major source of stress in delivering palliative care⁴⁴ and they find the psychological manifestations in managing dying patients hard to contend with³⁹. Physicians experience considerable stress in response to dealing with dying patients and their families, in particular when they have had a close relationship with a particular patient². This is a result of often suffering repeated losses due to the death of their patients, more so for female physicians who are more sensitive to the psycho-social issues of death. Younger physicians report more manifestations of stress and less coping mechanisms, while older physicians have less emotional involvement with their patients and as a result are more protected from the patients' anxiety. As already mentioned, no significant difference was found in terms of gender and age in our results, but it is possible that exploring emotional issues more deeply may yield a different result. In our results more doctors felt comfortable with emotional issues than those who felt palliative care to be a positive experience. One would expect it to be about the same, as the emotional care is often the more difficult part of managing terminally-ill patients, as already mentioned.

A very high percentage of 97% felt the involvement of the patient in decision-making to be very important and that the informed consent of the patient carries more weight than the wish of the doctor. This may indicate a positive attitude towards involving the patient in decision-making and that the wish of the patient is important. Whether this indicated attitude is applied in practice, was not further explored in the survey. At least it reflects on patient-centred care being seen as an essential aspect of palliative care, which is integral to the wider palliative care philosophy⁴⁰. Further study is needed on this particular aspect concerning wider communication, for instance informing patients about their diagnosis and prognosis, without which patient involvement in decision-making is not possible. It is known that what doctors think their patients want to know and what the patients and their families

actually want to know, may differ significantly². It has been shown that even though physicians may strongly agree that all patients should be informed about the terminal nature of their illness, as the outcome is better in terms of quality of life in those cases, in practice the reality may be completely different⁵⁸. In different geographical areas differences occur concerning how many patients were aware of the terminal nature of their diagnosis, which in some areas was a minority and in others the majority. In some instances the emphasis may be on patient autonomy and in others on beneficence and justice⁵⁸. Cultural backgrounds and values play an important role in end-of-life discussions⁸⁵. Individual culture is influenced by culture of the family, religion, spirituality, education, social class and personal preferences⁸⁵. This underlines the need for training in communication skills. Studies confirm that GPs frequently indicate that they lack training in communication skills^{72, 73}, an important GP competence⁷⁹. It still appears that joint decision-making is more the norm and that instances of patient-based decision-making are still low⁵⁸. Interaction between doctors and patients appears to be still very much physician dominated and not patient-centred, conflicting with what is being expressed by GPs⁵⁹. Communication often suffers because of physician discomfort due to a sense of failure to restore health to the patient or loss of hope in their own ability and where their own emotions impact on patient-centred communication⁸⁶. Further examination of this positive attitude expressed by our respondents to this particular question, will show whether this is applied in practice. This attitude is very encouraging and lays a foundation for improved communication. Other aspects of communication will be reflected on later in the discussion.

To a further attitude question, 82,93% of the respondents indicated that they need further training in aspects of palliative care. This finding is in line with other studies, indicating that GPs do realise areas of lack in training in palliative care and that they show a positive attitude to receiving further training in these areas^{72, 73}. As already mentioned, considering the age of the respondents in this study, very few, if any, would have received any undergraduate training in palliative care, as palliative care training was only recently introduced to the medical schools' curriculums. Even in countries where GP registrars do receive palliative care training, the actual time spent in training is limited. This still leaves significant areas where GPs feel that they lack adequate training and skills, especially in psycho-social issues and bereavement care⁸⁷. Other areas of palliative care identified by GPs

in which they need training were symptom control for non-cancer patients, drug-related topics like analgesics other than morphine and also in communication skills⁸⁸. Indicating a need for training does not reflect on competence or lack thereof⁸⁸. This openness and receptiveness for further training by the respondents, reflects on an attitude and not their competence. Discussion on the questions to follow, may give an indication of which particular topics the respondents in this study need further training on, and palliative care training for GPs will be discussed more extensively as well.

Even though further research is needed to explore the issues raised in the four questions on attitude towards palliative care, an overall positive attitude was shown by the respondents that may prove to be of great value in promoting the wider palliative care message amongst GPs and in primary care.

Belief:

As already mentioned a large variation was found in the desired answers to the four questions on belief, with an average of just less than two thirds of preferred answers for the four questions.

Family involvement:

In this section all the respondents recognised the importance of the involvement of the family in decision-making so as to ensure good palliative care management. This is a strong positive belief and in line with good communication and also underlines the earlier question relating to the importance of informed consent, which was answered positively by the majority of the respondents in the section on attitude. It is already known that the majority of terminally-ill patients will be cared for at home in the last year of their lives³⁸ with most patients desiring to die at home⁸⁹. This underscores the fact that the involvement of the family is of utmost importance in decision-making because a family member will most likely be the primary caregiver in most cases² and palliative care in the community will not be possible if the family is not involved. It is known that lack of support for the family, is often a reason why family and also patients will opt for admission to a hospital or palliative care centre instead of dying at home². There have been instances where patients have been critical of the support their families receive from GPs⁶⁸. Yet, in other instances there has

been a high level of satisfaction from carers for GP involvement, even when there was not optimal symptom control, indicating that the GP had time to discuss problems and carers felt involved⁶⁹. Often in these instances the wish to die at home was achieved. Therefore it is important for the GP to be aware of the patient's preference in terms of the choice of place of death⁹⁰ which makes it more likely for this goal to be achieved through the involvement of the family. As families often experience severe emotional distress when "bad news" is communicated to the families, preparation is needed and the preferences of the families understood. Their feelings need to be explored, their worries need to be listened to and they need to be supported and reassured⁹¹. There is an unmet support need of carers, who are often the family members. Therefore interventions need to be developed and implemented to meet this need, which again makes GP-involvement in all aspects of care of utmost importance⁹². When caregivers and the family are informed, there will be greater satisfaction with general practitioners' care and longer involvement with palliative care decreases the anxiety of family members before bereavement⁸⁶. Even though doctors will often find it harder to deal with the family than with the patients², the response from the participants in this study is very encouraging. The ways in which GPs involve the family in decision-making and how much of this actually happens in practice, have not been explored in the study. The belief that families must be involved is fundamental to realising palliative care within the community.

Team involvement:

Regarding the question relating to involvement in a multidisciplinary team and decision-making in the team, more than two thirds of the respondents felt that in the end decision-making rests with the general practitioner and more than two thirds of the respondents see themselves as the leader of the team. This response, to a certain extent, goes against an earlier positive attitude displayed where respondents felt that the informed wishes of the patient carry more weight than their own point of view. Within the multi-disciplinary team the leadership role revolves around motivation, guidance, facilitating the activities of the team and planning strategies, but in collaboration with the rest of the team². Decision-making through consensus will still be the approach, even if this takes time to allow for everybody involved to have a clearer understanding of the questions at hand and of the different viewpoints². In many instances, especially in rural areas and in under-resourced

medical services, the only help available to the GP may be untrained carers², far removed from the ideal of a multi-disciplinary team. From own experience and literature it is known that a GP will rarely have the luxury of a team in managing a patient during the terminal phase of an illness. In urban GP practices, hospice may be involved in caring for the patient, but most of the decision-making will rest on the shoulders of the GP, the only health professional involved. It will be done in conjunction with the patient and the family. This practical reality may explain the view to this question held by the majority of the respondents, but it needs to be explored in greater depth.

Bereavement care:

Bereavement care is an integral part of palliative care and constitutes continuity of care² that stretches beyond the patient and his / her death that underlines the holistic philosophy of palliative medicine. The fact that the greatest majority of participants to this study, believe that they have a necessary role to play in this final stage of care of the family, is very encouraging indeed, especially considering the fact that bereavement care is often an area in which GPs request more training⁸⁷.

Holistic approach:

It has been a disappointment that the greatest majority of participants were of the belief that the focus of palliative care should be on the physical symptoms and that that would ensure quality of life for the terminally ill. This indicates a lack of understanding of the wider palliative care principles of physical, psychological, spiritual and social care of the patient and the family to constitute quality of life and to enable the patient to live to the end, i.e. to view the patient as a “whole person”². Even when health care professionals are familiar with the concepts of palliative care, their attitudes, beliefs and self-perceptions may be strong barriers to delivering holistic care⁴⁹. That may be the case with the respondents in this study and the quality of the palliative care delivered will be affected if the “total pain” concept is not grasped². This concept needs to be established and explained through future educational efforts⁴⁹ to clarify the holistic care ethic. The broad concept of health and illness has to be embraced that an ethic of care can be emphasised for the whole of the medical profession, an ethic under pressure from technological advances and bureaucratic constraints⁹³. This particular question may perhaps have been formulated differently as

there is place for a “sometimes” option amongst the answers. The interpretation of the data will be influenced by this.

Knowledge and Practice:

The results on the questions exploring knowledge and practice in palliative care pointed to a number of wrong practices and areas where knowledge is lacking.

Aspects of pain management:

Again it was disappointing that only about one third of the respondents have grasped that apart from the physical aspect of pain, there is also psychological, spiritual and social aspects that need to be dealt with to achieve proper pain control^{2, 40, 52}. This finding strengthens the conclusion discussed in the previous paragraph that the greatest majority of the respondents do not understand the holistic approach in palliative care management. This then underlines the fact that this particular concept has to be promoted and established amongst GPs to ensure good palliative care delivery.

On the positive side more than 80% of the respondents were not concerned with respiratory depression when high doses of morphine are used, a concern which has been mentioned in other studies⁵⁴. Some studies indicate that GPs have no problem in using high doses of morphine for pain in cancer conditions, but there is reluctance to use opioids for pain in non-malignant conditions⁵⁴, an aspect not dealt with in this questionnaire. A preparedness to use high doses of opioids in pain control is important as it is still regularly reported that cancer patients' pain is not well controlled⁵², that patients are often under medicated⁵⁵ and that GPs' performance in providing optimal pain and symptom control is questioned³⁹. The respondents in this study appear to be willing to increase dosages of opioids for increasing pain, but this needs to be surveyed further as GPs often have problems in assessing pain accurately³⁹ and believe that patients are happy with their pain management⁵⁴, when it is not the case. This is in spite of the fact that most GPs regard pain as easy to control and are comfortable with the use of opioids. Research also suggests that GPs should be able to manage cancer pain⁵².

Very few participants were concerned about addiction when using high dosages of morphine for pain control. A concern about dependency is often a reason why GPs are

reluctant to use opioids in dosages adequate to control pain^{53, 54} and also hesitant out of fear of official scrutiny by regulatory bodies when opioids are prescribed in high doses⁵⁴. Increasing requests for analgesics are often seen as being due to drug tolerance, rather than disease progression⁵⁵. The lack of concern about addiction or psychological dependency is important in this study, indicating that there may be more freedom and knowledge about pain control in prescribing opioids, but this has to be explored in more detail.

Some information was also gained from questions relating to practical aspects of prescribing drugs in pain management. Almost half of the respondents indicated that they will use different opioids in combination, believing that it has a synergistic effect, a practice that will negatively impact on pain control. This may explain why the majority of doctors believe their patients to be happy with pain control when the opposite is true⁵⁴. It seems that health care professionals can get fixed in their prescription behaviours, without questioning the outcome of their action⁵⁵. It is possible that GPs in the study do have the knowledge, but as is known, knowledge often does not realise into practice³⁹.

Use of laxatives:

A further positive finding was that the overwhelming majority of GPs in the study will routinely use a laxative when prescribing opioids. This is a therapeutic practice that many physicians still get wrong⁵⁴ and terminally-ill patients often develop constipation because laxatives are not prescribed routinely⁵¹. The respondents in this study fared much better in this particular practice than their counterpart elsewhere^{51, 52, 54, 55}. However, they did not answer so well when it came to the routine use of an anti-emetic when initiating an opioid for pain control; only about a quarter of physicians will use an anti-emetic routinely in these circumstances, meaning that they did not practise this aspect of control of morphine side-effects as well as their colleagues^{52, 54, 55}. This may also indicate that nausea is not a symptom often diagnosed and may be missed if not asked about specifically³⁹.

Hypodermoclysis:

The subcutaneous route is an effective and valid way of delivering drugs and medication in palliative care² and is widely used in palliative care delivery, especially in the U.K.⁹⁴. It is of concern that only slightly more than half of the participants in this study were aware of this

practice and agreed with the statement, thereby indicating that only half of the respondents will use this route. The quality of palliative care delivery may be compromised and those health care professionals will not have this administration route at their disposal due to lack of knowledge. Half of the respondents indicated that they were familiar with the use of syringe drivers in palliative care delivery. In the UK syringe drivers are widely used⁹⁴ as a means of continuous administration of drugs via the subcutaneous route. Yet GPs in the United Kingdom also indicated that they need more training in the use of syringe drivers⁷¹. If this need exists in the UK where palliative care training is much more prevalent⁷⁴ in comparison to South Africa³⁵, one has to question the response to this question by the participants. This perceived knowledge on aspects like the advantages and disadvantages of the use of syringe drivers, drug use with syringe drivers and the compatibility of drugs when combined in syringe drivers, has to be explored further.

Intravenous fluids:

Regarding the use of intravenous fluids in the final stages of disease when fluid intake is declining, the majority of participants felt that it is indicated to use this intervention. A number of aspects flow from this particular question, for instance that respondents may use intravenous fluids because they may not be aware of hypodermoclysis. This is supported by the fact that only half of the GPs in this study are aware of the subcutaneous route to deliver drugs and fluids. It may also be assumed that GPs are unfamiliar with the fact that fluid intake declines in the final stages of disease⁹⁵ and thus poses the question whether they are familiar with the changes taking place in the final stages before death occurs. It is known that intravenous intervention will often be employed as a psychological measure at the insistence of the family², but the medical evidence is conflicting and this practice remains controversial². Dehydration can cause a number of symptoms like cognitive impairment, agitation, delirium, myoclonus and drug toxicity⁹⁶. Even though it has been reported that giving patients 1000 ml of fluid by hypodermoclysis, significantly improved symptoms⁹⁵, a number of arguments are raised against this practice as there are fewer respiratory problems, oedema and ascites when parental fluids are withheld. Parental fluids may prolong dying and parental hydration is uncomfortable and limits mobility⁹⁶. A literature overview concludes that some dying patients may not suffer any ill-effects from dehydration, but on the other hand there may be others who may benefit from parental

hydration⁹⁶. Because this intervention has ethical considerations, the involvement of the patient and family in decision-making is of the utmost importance, weighing benefit and burden in each individual case⁹⁷. The responses to this question by the participants in the study, with almost half for and half against, underscore the complexity and controversy to this question. This will need to be examined in more detail in further studies.

Palliative care emergencies:

An overwhelming majority of respondents are aware that there are emergency situations in palliative care that call for immediate action to improve outcomes. This indicates the knowledge that even in a terminally ill patient, intervention may improve quality of life in seemingly hopeless situations. Whether the participating GPs are aware what those emergency situations are, was not examined. In a next question relating to spinal cord compression, almost all the doctors knew that there was much to offer clinically in these cases and not just to abandon these patients. Whether they have knowledge of what the emergency action will be, was not investigated. Even though this is a positive response to a very important aspect in palliative care, these two questions are not exploring responses in depth. Understanding these emergencies, anticipating them and knowing how to manage them, is of utmost importance to determine outcomes so as to achieve a “good death”⁹⁸. Obviously these actions will be determined by the informed choice of the patient and the goals that were previously determined to maintain quality of life. These emergencies often do not draw immediate emergency response as in the normal emergency setting. Yet they are crises that are an important turning point in the course of the disease, even though death is to be expected⁹⁹. All of these aspects were not investigated in the questionnaire in this study, due to the study being very broad, with the result that it is uncertain whether respondents really understand the importance thereof and what the extent of their actual knowledge is.

Ethical principles:

The overwhelming majority of respondents indicated that they use ethical principles in decision-making in palliative care and this underlines an attitude discussed previously where doctors felt it to be very important to involve the family in decision-making and where informed consent was deemed to be important. Whether this happens in practice we do not

know from this questionnaire, as a positive answer does not necessarily mean that it is practised³⁹. The understanding of the meaning of these ethical principles was not tested in the questionnaire, which leaves a void, but again fell outside the scope of this study which was a broad overview. The principles mentioned in this question form the foundation upon which approaches to care and treatment decisions are based, whereby the inherent worth of each person is acknowledged¹⁰⁰ and the best interest for each individual patient is sought according to their social, cultural and spiritual values². A more in-depth survey around these ethical principles, may show how well doctors understand these principles and whether it is practised as it is claimed, which is of course of great importance to ensure proper palliative care. At the most we can conclude that respondents are aware of the importance of ethics and with that there is a good possibility that they will apply it in practice.

Education:

At the beginning of this discussion it was stated that the greatest part of palliative care will be delivered by primary care physicians who understand the palliative care concept, have received basic palliative care training and are familiar with symptom control in terminal care⁷⁸. Even though there is an overall positive attitude towards palliative care amongst the respondents, there is a lack of grasping the wider holistic approach to terminal care, which is to care for patients on a physical, psychological, spiritual and social level¹. This is a concern, as it has the potential to undermine service delivery greatly and this raises the question of how well the holistic palliative care message has reached practising GPs. This is an indication of the lack of training for GPs in palliative care, as palliative care was only introduced to undergraduate training recently³⁵ and this also questions the ability of GPs to deliver quality palliative care. Considering the age of the respondents in this study one can safely say that it is unlikely that many of them received specific palliative care training³⁵. Apart from that, palliative care topics rarely feature in South African medical journals and I, personally, have never been to a continued medical education meeting where palliative care was taught. Although some questions were answered well, it is also clear from the above results that there are a significant number of areas where GPs lack knowledge and are making use of wrong practices, again underlining the lack of past training³⁵ and the need for future training. Training is of the utmost importance, if in the face of an increased demand for palliative care in the future proper terminal care is to be delivered to meet this demand.

As stated in the introduction to this study, health authorities and health care professionals can expect a huge increase in the demand for terminal care in the years ahead and that the brunt of this is going to be on the shoulders of primary health care professionals³⁴, as this service delivery will mostly be through home-based care⁸. As stated under the WHO minimum standards, training and education of health care professionals and raising public awareness are needed to develop minimum standards of palliative care delivery⁸. Thus, apart from the WHO resolutions expecting training of health professionals to be integral to service delivery, the lack of knowledge and incorrect practices and beliefs as demonstrated in this study, necessitate further training of practising family physicians if palliative care outcomes are to be improved. What is an encouraging finding in this study is the overall positive attitude and willingness for further training of the participants. This same openness towards training was found in other studies⁷⁶, reflecting their perceived need for further training and not their actual competence⁷⁵. How to approach the education of GPs will need careful consideration, as it is accepted that the traditional forms of education are not effective in changing clinical behaviour¹⁰¹ and education will need to be tailored along the preferences of the GPs to ensure the best response. It is reported that there is at present a shift in educational methods in general practice with a move towards individual and practice-based learning⁷⁵ and to positively affect clinical outcomes, education needs to be interactive, case-based and personalised to individual doctors according to their needs and clinical setting¹⁰¹. Different settings will call for different educational needs and preferences⁷⁵. Practical sessions and the review of clinical cases in a small group setting, seems to be a preferred method of education for GPs and for palliative care to be part of CME programmes⁷⁶. There is proof that the attendance of a palliative care workshop has substantial benefit¹⁰¹. This resulted in significant improvement in clinical confidence in palliative care knowledge and skills in managing common palliative care symptoms, with also positive change in attitudes towards other issues relating to the management of palliative care patients, such as psycho-social aspects¹⁰¹. Current literature indicates that doctors worldwide are not receiving adequate undergraduate nor postgraduate training in palliative care, and a postgraduate course in palliative care has shown improved communication skills and skills in symptom management⁷¹. A meta-analysis of 46 controlled outcome-based studies showed that cognitive learning goals can be achieved through education, resulting in changed attitudes and behaviours relating to death issues¹⁰². A

number of topics have been indicated by GPs where they feel that they need further palliative care training: symptom control for non-cancer patients, analgesic use other than opioids, nausea and vomiting control, opioid prescription, using syringe drivers, counselling and communication skills⁷⁵. These topics correspond closely with the needs of Irish GPs⁷⁶. From the questionnaire used in this study, a number of areas were highlighted where there was lack of knowledge, wrong practices and beliefs, for example understanding the wider holistic approach of palliative care, lack of knowledge about using the subcutaneous route for drug delivery, wrong practices and knowledge concerning the use and prescription of opioids and other drugs. The topics correspond to a certain degree with the ones mentioned in the studies above, which then identifies areas on which training needs to be focused as this need has been identified.

Within the South African context where practising GPs have received very limited, if any, palliative care training, there is an enormous opportunity to improve knowledge and change attitudes, beliefs and practices through education. Exploring the preferred educational methods has to be done to bring about these changes. Serious consideration has to be given to who must take responsibility for providing this education, the method to be used and obviously, how this is to be funded, as the majority of GPs are involved in private health care and are under time constraints to generate an income for themselves. The answers to these questions are outside the scope of this study, but will need urgent attention if any significant improvement in the quality of the palliative care given by GPs is to be achieved. From personal experience I can report that this education is not reaching GPs at present. Education will also do much to improve the confidence of family physicians in delivering palliative care and to empower them to embrace as their own the responsibility of the end-of-life care of their patients. As already mentioned, they are best positioned for the role of organizing and delivering palliative care and yet primary care workers report problems in obtaining relevant training and education and they often feel themselves unsupported and at times overwhelmed in fulfilling that role¹⁰³. Acknowledgement of the importance of the role of family physicians in palliative medicine by others involved in cancer, chronic disease and HIV care, is needed and this has to be supported with definite interventions in practice.

In developed countries, palliative care services mostly developed in urban populations where population density allowed for specialist cancer services to be implemented, whereas

in rural populations, with a different environment, infrastructure and resources, primary care professionals are looked upon to play the crucial role of delivering palliative care¹⁰³. In South Africa hospices are in operation in the urban areas and in some of the bigger semi-rural towns, leaving vast rural areas without palliative care services. The hospices are non-governmental organisations, registered as charities. They have no income from government resources and rely on community support for finances³⁰, leaving them resource strapped, to the extent that even in urban areas difficulty is experienced in coping with the need. This is also due to the huge burden of care for HIV patients³⁰. A few of the respondents indicated on their questionnaires that they do work closely with the hospice in their area. This particular aspect was not explored in the questionnaire, but respondents showed a positive attitude towards teamwork where the majority saw a leadership role for themselves. There seems to be openness towards a shared model of care. GPs have often shown themselves to be positive towards a multi-disciplinary team approach and a need to be part of a team^{65, 66}. The Gold Standards Framework was introduced in the UK with the aim to develop a locally based system to improve the quality of care for patients and their carers during the last months of life and to optimise the organisation of such care¹⁰⁴. This involves improved communication by the processes of identifying patients in need of palliative care, assessing their needs, symptoms and preferences and to plan care around that. The practices where this approach was implemented, reported that registers were set up for patients receiving palliative care, regular multi-disciplinary team meetings were held and they were confident that good palliative care was being delivered³³. A qualitative study of the practices incorporating the programme found that palliative care patients were being identified and communications have improved, resulting in improved care planning and greater confidence in symptom control from clinicians¹⁰⁵. Problems are still being experienced around commitment to individual practices and communication between different role players¹⁰⁵, but this is outweighed by the positive aspects. Practices with effective organisation and good relationships appear to be much better placed to deliver quality palliative care consistently¹⁰⁶. A properly developed model of shared-care has proved to be of great value to clinicians and patients alike¹⁰⁷. Such a program has greatly increased the capacity of family physicians to deliver palliative home-care through screening and case-finding in family practice offices, improving confidence, skills and knowledge through practice-based education and sharing clinical care by having access to palliative care experts¹⁰⁷.

Programmes as the above do a lot to “officially” acknowledge the role that GPs have to play in palliative care delivery, empowering them to take the palliative care responsibility as primarily their own, which is very necessary if palliative care is to be delivered effectively in GP practices. Having any of this in practice for the South African GP is still only a future goal, as there is little acknowledgement of the importance of the role the GP has in palliative care delivery within the wider health care system. The majority of the South African GPs’ cancer patients will receive treatment at a private institution under the care of an oncologist in private practice. Even though the majority of oncologists feel strongly that they should co-ordinate care, also end-of-life care, the reality is that very few oncologists are involved in practising palliative care¹⁰⁸. Co-operation with other palliative care clinicians and services is low and there are indications that their perceived competence in symptom management is not reflected in practice. This indicates a need for organizational changes to ensure better palliative care in practice¹⁰⁸. There is also acceptance of the idea that there is a need for medical oncology and palliative care to be integrated, so as to involve palliative care much earlier in the disease trajectory and also to involve a wider team of caregivers, which will then involve the family physician as well¹⁰⁹. Care models for the terminally ill, are diversified in each country and are determined by and dependent upon health and academic systems and health care financing¹⁰⁹. The active involvement of GPs in South Africa by private oncologists in the cancer care of that particular GPs’ patients will do much to encourage GPs to be more involved in palliative care and to empower them to take responsibility for the palliative care of their patients. Apart from that, as already stated, they are better positioned than specialists to deliver this care within the home of the patient. The same can be said of the palliative care delivery to patients with AIDS and chronic disease, where involvement of GPs by specialists in patient management and even public hospitals caring for those patients, will help to spread the palliative care message. This may pave the way to begin to look at more developed care models, like the Gold Standard Framework, with the aim to improve patient care. To implement changes in organisation, there is a need for changes in attitudes, beliefs and behaviour, resulting in teamwork, effective teaching and training and good communication¹¹⁰. This again underlines the fact that there is much groundwork to be done with all involved in palliative care, to effect these organizational changes, which will then result in GPs being better equipped to deliver the service. The approach of health funders towards GPs’ delivering home-based palliative care has to

change in terms of acknowledging the importance of their role as well as the approach to remuneration. This will do much to get GPs more actively involved in palliative care. In this study the GPs showed a willingness to be involved in palliative care and acceptance of that role, a willingness to receive further training to improve knowledge and establish the correct practices and beliefs. Further debate and funding will be needed for “somebody” to step forward to take responsibility to facilitate this so that the role of GPs in primary palliative care can be established permanently.

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CONCLUSION AND RECOMMENDATIONS

GPs demonstrate a positive attitude towards palliative care, but there are areas where they lack in knowledge, with some incorrect practices and beliefs that will affect their service delivery to their patients, mostly due to lack of palliative care training in the past. They can therefore be better equipped to deliver a palliative care service by definite and effective educational interventions that will effect change, so as to establish and acknowledge the importance of the role that GPs have to play in the future to deliver palliative care to a growing number of patients suffering from life-threatening illnesses. They are receptive towards palliative care and open for further training.

The importance of the role of the GP in palliative care has to be advocated actively by health authorities and health funders, but also recognized by specialists in cancer care and chronic disease management. Medical schools have to embark on an active program to further educate and train practising GPs through CMEs (continued medical education) or other programmes preferred by the GPs. Pharmaceutical companies must be approached for sponsorship for such programmes.

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APPENDIX 1

INFORMATION TO PARTICIPANTS IN THIS STUDY

THE KNOWLEDGE, ATTITUDES, BELIEFS AND PRACTICES OF GENERAL PRACTITIONERS TOWARDS PALLIATIVE CARE

Dear Colleague,

Thank you for spending the time in reading this information and taking the time in answering the enclosed questionnaire.

I am a general practitioner with twenty years experience as a GP in a rural practice. I qualified from the University of Stellenbosch in 1980. At present I am enrolled as a part-time student at the University of Cape Town for a Masters in Palliative Medicine.

Palliative care involves the care of terminally ill patients. Although palliative medicine is recognised as a specialised field in some overseas countries, it is a new discipline in South Africa. Even though we are often dealing with terminally ill patients in the course of GP practice, very few of us as practising GP's have received official training in the principles of palliative medicine. All indications are that we shall be dealing with increasing numbers of patients in need of such care. There is a strong view amongst some people working in palliative care, that terminal care is the domain of the GP and should stay primarily their responsibility. In the light of this, we need to assess ourselves from time to time and this then has been the reason for this study.

The aim of this study is then to assess how well we as GP's are equipped to manage patients in need of terminal care. This is to receive insight into the interventions needed, if any, to ensure that we deliver good care to our patients and their families in the face of death and in their final days.

I shall greatly appreciate your taking the time to fill out the enclosed questionnaire and returning it in the addressed enclosed envelope, within one week of receiving it, please. It will take about 10 minutes of your time. I want to assure you that all questionnaires will be handled in confidence and that the identity of participants will only be known to the researcher for the purpose of follow-up.

The results from the study will be conveyed to all participants and the aim is to have it published in a reputed medical journal.

Kind regards and thank you,

C.J. Loftus

P.S. This information sheet will be available in Afrikaans as well

APPENDIX 2

QUESTIONNAIRE

THE KNOWLEDGE, ATTITUDES, BELIEFS AND PRACTICES OF GENERAL PRACTITIONERS TOWARDS
PALLIATIVE CARE.

Thank you for answering this questionnaire. Please mark your answer with an X in the appropriate box or fill in the information requested.

DEMOGRAPHIC INFORMATION:

Year of qualification:

Gender

Male / Female

Age

Location of practice:

Rural / Semi-urban / Urban

Years in GP practice

Number of terminally ill patients

managed in a year

0 – 5 / 5 – 10 / 10 – 15 / > 15

QUESTIONS:

1. Even though it may challenge me, managing a patient with life-threatening or terminal illness, is mostly a positive experience.

YES / NO

2. In my opinion, the focus of palliative care is on the management of physical symptoms to ensure quality of life for patients with life-threatening diseases.

YES / NO

3. In decision-making on palliative care management, the patient's informed wish carries more weight than the advice of the health care professional.

YES / NO

4. The involvement of the patient's family in decision-making is necessary for good palliative care management.

YES / NO

5. Morphine cannot be titrated to high doses, because of the danger of respiratory depression.

YES / NO

6. In pain management, controlling the physical aspects of the pain, will determine successful pain control.

YES / NO

7. There are emergency situations in terminally ill patients that call for immediate action.

YES / NO

8. As he / she is heading the multidisciplinary team, the doctor should make the final decisions in managing a patient with a life-threatening illness.

YES / NO

9. Addiction is a relevant concern when patients are using high doses of morphine to control chronic pain.

YES / NO

10. In a patient with vertebral metastases, who develops weakness of the legs, there is much more to offer in terms of clinical care.

YES / NO

11. In my practice I use different opioids in combination to gain a synergistic action.

YES / NO

12. Initiating intravenous fluids is indicated in a terminally ill patient whose oral intake has declined significantly.

YES / NO

13. I am familiar with the use of syringe drivers as a means of administering drugs.

YES / NO

14. Using the subcutaneous route is an effective way of delivering drugs and fluids in a terminal patient.

YES / NO

15. The ethical principles of autonomy, beneficence and non-maleficence will in most cases guide me in decision-making in palliative care.

YES / NO

16. It is a good practice to prescribe a laxative for my patient who is on opioid medication.

YES / NO

17. In my drug regime for symptom management, I only prescribe an anti-emetic when the patient has symptoms of nausea.

YES / NO

18. I am uncomfortable with emotional issues and it is better dealt with by others like the counsellor.

YES / NO

19. After the death of the patient, my involvement with bereavement care of the family is important.

YES / NO

20. I do not need further training in palliative care, as I feel comfortable with my knowledge and skill.

YES / NO

Questionnaire number:



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20th May 2012

Re Dr Neil Loftus – corrections to dissertation

Dear Adri,

Dr Cornelius Loftus has worked on the corrections to his dissertation with advice from myself, Prof Richard Harding and Rauf Sayed following the recommendations from the external examiners and dissertations committee.

I have reviewed his final submission and am satisfied that he has addressed the external examiners' comments adequately. He has made the required corrections to his final dissertation and submits it now for re-examination by Prof Geoff Mitchell.

Yours sincerely

Liz Gwyther

Letter to examiners:

15 MAY 2012

Dear Prof Mitchell and Dr van Deventer,

Thank you for the comments and advice in your examination of the mini-dissertation: The knowledge, attitudes, beliefs and practices towards palliative care of family physicians in the Boland and northern suburbs of Cape Town. The changes I have made and have listed in the attached document strengthen the dissertation

Your sincerely,

A handwritten signature in black ink, appearing to read 'C. Loftus', written in a cursive style.

Cornelius Loftus